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PROPOSALS TO IMPROVE THE SUPPLEMENTAL SECURITY INCOME PROGRAM

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES

OF THE

COMMITTEE ON WAYS AND MEANS
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

MAY 30, 1989

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PROPOSALS TO IMPROVE THE SUPPLEMENTAL SECURITY INCOME PROGRAM

TUESDAY, MAY 30, 1989

HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON HUMAN RESOURCES,
Washington, D.C.

The subcommittee met, pursuant to call, at 1 p.m., in room B-318, Rayburn House Office Building, Hon. Thomas J. Downey (acting chairman of the subcommittee) presiding.

[The press release announcing the hearing follows:]

FOR IMMEDIATE RELEASE
THURSDAY, APRIL 27, 1989

PR #11
SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES
1102 LONGWORTH HOUSE OFFICE BLDG.
WASHINGTON, D.C. 20515
TELEPHONE: (202) 225-1721

THE HONORABLE THOMAS J. DOWNEY (D., N.Y.), ACTING CHAIRMAN, SUBCOMMITTEE ON HUMAN RESOURCES, COMMITTEE ON WAYS AND MEANS, U.S. HOUSE OF REPRESENTATIVES, ANNOUNCES A HEARING ON PROPOSALS TO IMPROVE THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

The Honorable Thomas J. Downey, (D., N.Y.), Acting Chairman, Subcommittee on Human Resources, Committee on Ways and Means, U.S. House of Representatives, today announced a public hearing on proposals to improve the Supplemental Security Income (SSI) Program. The hearing will be held on Tuesday, May 30, 1989, beginning at 1:00 p.m., in room B-318 Rayburn House Office Building.

In announcing this hearing, Chairman Downey stated: "On March 2, 1989 the Subcommittee on Human Resources held a joint hearing with the Select Committee on Aging on the SSI program. At that hearing, I learned that some low-income aged, blind, or disabled persons might not benefit from SSI, either because they do not know about it, they are misinformed, or they fall through the cracks between arcane and out-of-date program rules. At this hearing, the Subcommittee will hear testimony about proposals to correct some of these problems."

Testimony at the hearing will be taken from public witnesses. The Subcommittee is particularly interested in the issues identified below.

SSI Outreach

The Social Security Administration (SSA) presently conducts outreach campaigns to inform individuals who may be eligible for SSI. It disseminates press releases, radio spots, questions and answers, and speech material to local SSA offices to assist local SSI outreach efforts. In addition, legal and welfare agencies and advocacy groups continue to assist SSA in finding potentially eligible SSI recipients. However, the Subcommittee would like to determine whether SSA is doing enough. In particular, should Congress pass legislation requiring SSA to conduct specific, ongoing outreach activities? Should SSA be required to establish special outreach activities for disabled children?

Disabled Children

Some disabled children do not receive SSI benefits because: they do not fit into the specific categories of disability outlined in SSA's childhood listings of impairments; they are too young to be tested for a disability; or the listing of impairments is out-of-date. Unlike adults, they are not given individual functional assessments. The result is that some disabled children are not eligible for SSI. The Subcommittee is interested in proposals that would aid these disabled children.

With regard to disabled children, witnesses should address the following questions: Should children receive individual functional assessments and if so, what should they entail? Should Congress require SSA to use pediatricians to perform the assessments? Should the childhood listings of impairments be updated? Should children with severe genetic and congenital diseases be presumed disabled until such time as medical professionals can test them for disability? If disabled children can be cared for appropriately at home at a lower cost than in institutions, should Congress allow these children to receive Medicaid benefits and the SSI personal needs allowance of $30 per month?

(MORE)

Other Issues

A variety of other SSI issues have also been raised. With regard to disabled adults, the problems of those "living in the household of others" appear to be especially acute. In particular, should Congress change the one-third benefit rules for those receiving maintenance and/or support while living in the household of another person? Other issues are whether Congress should require SSA to average weekly or bi-monthly paychecks on an annual basis so that some SSI recipients are not denied benefits in the months in which they receive an extra check and whether the SSI benefit level and asset test should be adjusted.

DETAILS FOR SUBMISSION OF REQUESTS TO BE HEARD:

Individuals and organizations interested in presenting oral testimony before the Subcommittee must submit their requests to be heard [(202) 225-1721] no later than the close of business, Friday, May 19, 1989. The telephone request must be followed by a formal written request to Robert J. Leonard, Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. The Subcommittee staff will notify by telephone those scheduled to appear as soon as possible after the filing deadline. Any questions concerning a scheduled appearance should be directed to the Subcommittee [(202) 225-1025].

It is urged that persons and organizations having a common position make every effort to designate one spokesperson to represent them in order for the Subcommittee to hear as many points of view as possible. Time for oral presentations will be strictly limited with the understanding that a more detailed statement may be included in the printed record of the hearing. **(See formatting requirements below.)** This process will afford more time for members to question witnesses. In addition, witnesses may be grouped as panelists with strict time limitations for each panelist.

In order to assure the most productive use of the limited amount of time available to question witnesses, all witnesses scheduled to appear are required to submit 100 copies of their prepared statements to the Subcommittee office, B-317 Rayburn House Office Building, at least 24 hours in advance of their scheduled appearance. Failure to comply with this requirement may result in the witness being denied the opportunity to testify in person.

WRITTEN STATEMENTS IN LIEU OF PERSONAL APPEARANCE:

Persons wishing to submit a written statement for the printed record of the hearing should submit at least six (6) copies of their statement by the close of business, Tuesday, June 13, 1989, to Robert J. Leonard, Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. If those filing written statements wish to have their statements distributed to the press and interested public, they may deliver 100 additional copies for this purpose to the Subcommittee office on the day of the hearing.

FORMATTING REQUIREMENTS:

Each statement presented for printing to the Committee by a witness, any written statement or exhibit submitted for the printed record or any written comments in response to a request for written comments must conform to the guidelines listed below. Any statement or exhibit not in compliance with these guidelines will not be printed, but will be maintained in the Committee files for review and use by the Committee.

1. All statements and any accompanying exhibits for printing must be typed in single space on legal-size paper and may not exceed a total of 10 pages.
2. Copies of whole documents submitted as exhibit material will not be accepted for printing. Instead, exhibit material should be referenced and quoted or paraphrased. All exhibit material not meeting these specifications will be maintained in the Committee files for review and use by the Committee.
3. Statements must contain the name and capacity in which the witness will appear or, for written comments, the name and capacity of the person submitting the statement, as well as any clients or persons, or any organization for whom the witness appears or for whom the statement is submitted.
4. A supplemental sheet must accompany each statement listing the name, full address, a telephone number where the witness or the designated representative may be reached and a topical outline or summary of the comments and recommendations in the full statement. This supplemental sheet will not be included in the printed record.

The above restrictions and limitations apply only to material being submitted for printing. Statements and exhibits or supplementary material submitted solely for distribution to the Members, the press and public during the course of a public hearing, may be submitted in other forms.

Acting Chairman DOWNEY. The subcommittee will come to order.

Today we will hear testimony on proposals to improve the SSI program. In announcing this hearing I noted that some low-income aged, blind, or disabled persons don't benefit from SSI, either because they don't know about it, they are misinformed, or they fall through the cracks between arcane and out-of-date program rules.

At this hearing I hope to hear more about these problems and how to correct them.

First, we know that the Social Security Administration conducts outreach campaigns to inform individuals who may be eligible for SSI. However, I wonder whether this is enough, given evidence that only half of those eligible for SSI actually receive it. Do we need legislation requiring ongoing outreach activities not only for adults, but for disabled children as well?

Second, some disabled children do not receive SSI benefits because: their disabilities do not fit into the current listing of childhood impairments; they are too young to be tested for a disability; or the listing of childhood impairments is out-of-date. Also, there are some children who could be cared for more economically at home than in a hospital, but cannot go home because they would lose SSI and Medicaid eligibility if they leave the hospital. What should be done to help these children?

Third, we need to consider the economic status of SSI recipients. Are those recipients living in the household of others treated fairly by the one-third reduction in their benefits? Should SSI resource limits and benefit levels be increased?

Those are the issues. We have an ambitious list of distinguished witnesses with a limited amount of time, so let's begin.

We are privileged and honored to hear from three of our colleagues. First Mr. Donnelly, a member of the Ways and Means Committee.

Brian, we will hear from you first.

STATEMENT OF HON. BRIAN J. DONNELLY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MASSACHUSETTS

Mr. DONNELLY. Thank you very much, Mr. Chairman, for holding this hearing on the SSI program and on legislation I have filed, H.R. 1525, which I think would make a significant and needed reform to the SSI program. Let me say, it is very nice to be back here appearing before my old subcommittee on which I was proud to serve in the past Congress.

I will make my remarks brief because also testifying before you today is Kathleen Mulligan of Methuen, Massachusetts. Mrs. Mulligan's personal situation is the reason I introduced H.R. 1525 and I think her comments will be helpful to the subcommittee as you begin drafting reforms to the SSI program.

Congressman Chester Atkins and I introduced H.R. 1525 on March 21 of this year. Quite simply, the bill waives the "income and resource deeming" rules under the SSI program in the case of severely disabled children who could be cared for less expensively—and more importantly, more humanely—at home. The purpose of my bill is to correct an absurd policy of the existing law which

actually encourages families to keep their disabled children institutionalized.

Under current law, an individual under age 65 is only entitled to SSI benefits if they are severely disabled and are low income. So, if a disabled child is hospitalized, they generally qualify for an SSI benefit—and also Medicaid—since they have no income.

The problem arises when the child returns home from the institution, because the law requires that the parents' income and resources be "deemed" to the child. Unless the parents are very low income, their income and resources make the child ineligible for SSI.

Mr. Chairman, the unfairness and, I might say, absurdity of this aspect of the law is clear. Even though it is far more expensive to care for these children in an institution, the children qualify for a benefit there, but lose it when they return home. This blatantly discriminates against working-class families.

H.R. 1525 would reverse this aspect of current law. The bill would waive the income and resource deeming rules if a severely disabled child were moved out of an institution and returned home, thus qualifying the child for the SSI monthly personal needs allowance and Medicaid. This bill is a responsible and humane approach to a bizarre feature of current law.

Let me address head-on the question of cost. The Congressional Budget Office has prepared a tentative cost estimate of H.R. 1525. They estimate that the bill will cost $715 million over 3 years.

I recognize that these numbers are high. But let me say, first of all, that I am more than willing to find the revenue we would need to pay for this bill. And second, I understand that staff is meeting tomorrow to discuss a way to cut down on the costs of this bill, and I will accept any recommendations of the staff which retain the principles of H.R. 1525.

Mr. Chairman, this legislation is sound and responsible. I want to personally thank Mrs. Mulligan for all of her efforts in calling this issue to the attention of Congress—and, in fact, to the attention of President Bush in last year's Presidential campaign. I might say in closing that I find it a bit absurd that the mother of a disabled child has to petition the President of the United States for access to adequate health care. But Mrs. Mulligan's persistent efforts have resulted in this hearing today. I urge the members of the subcommittee to listen closely to her testimony, and I urge your support for H.R. 1525.

Thank you. I look forward to working with you, Mr. Chairman and the members of the subcommittee to see if we can craft a package that will address the dire needs of these children and their families and also deal with the fiscal realities we presently find ourselves in.

Acting Chairman DOWNEY. Thank you.

STATEMENT OF HON. STEVE BARTLETT, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Acting Chairman DOWNEY. Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman, I ask to submit my full testimony in the record and I will highlight it.

Acting Chairman DOWNEY. Without objection.

Mr. BARTLETT. I have prepared for the subcommittee a full description of H.R. 8 and the compromise for H.R. 8. H.R. 8 which is entitled, "the Social Security Work Incentives Act," is the SSDI equivalent to section 1619 of the SSI legislation which this subcommittee was so instrumental in passing two sessions ago.

H.R. 8 legislation was introduced earlier in this session on the opening day. The original cosponsors include Mr. Archer, Mr. Matsui, Mr. Levin, Mr. Gradison, and myself and is now up to 176 cosponsors. The essence of H.R. 8 as originally introduced is to allow persons who otherwise want to and are eligible to go to work but for their absence of health insurance and retain their health insurance as they would be able to do if they stayed unemployed.

I want to call to the committee's attention the last quarter in which measurements were taken on section 1619 saw that the streamlining of SSI health insurance benefits and the automatic reinstatement increased those persons eligible for SSI who are now working by some 20,000.

For those receiving no cash benefits under 1619(b) that represented a 25-percent increase in a relatively short time period of which the only change has been the availability of section 1619 and therefore Medicaid and health insurance. Originally H.R. 8 as introduced contained three major sections. Most significantly it contained a Medicare buy-in so someone who is otherwise eligible to receive Medicare free if they stay unemployed would be given the opportunity if they go to work and have no other access to health insurance to buy into Medicare on a sliding scale.

That would come under Mr. Stark's Subcommittee on Health. H.R. 8 would have provided for a cash offset comparable to that in section 1619 of a $1 reduction of cash benefits for every $2 in earnings. That would come under Mr. Jacobs' Subcommittee on Social Security.

Third is a series of technical but very essential and meaningful amendments that would come under the jurisdiction of this subcommittee in which I will go into some detail today.

What the sponsors and cosponsors of H.R. 8 have done was to delete the cash offset not because we wanted to but because that seemed to be the portion that generated the most opposition based on budgetary grounds. Since most of the benefits are gained by the section in this subcommittee, the technical portions which allow someone eligible for SSI and/or SSDI to opt into one or both, those are the least costly and the maximum benefits.

What we are proposing to you today is that this subcommittee adopt the SSDI–SSI portion under this subcommittee's jurisdiction; the Health Subcommittee adopted the Medicare buy-in and the other subcommittee continues to work on and think about the cash offset section.

So what is the Human Resources Subcommittee's jurisdiction. First on page 2 of my testimony, is the element of the compromise that essentially says that if a person is otherwise eligible for SSI but is on SSDI, we would allow that person to opt into SSI if it is better for that person to be on SSI under section 1619 program and working.

There are two reasons that a person would choose to opt into SSI if they otherwise could receive SSDI. The first is a description of a constituent, Pete Stark, provided from California. I have described that person on page 4 of my testimony. His first name is Harry. He is disabled. He has been receiving SSDI benefits of $570 a month, that is above the SSI income limit and therefore he is not eligible for SSI. He has a job he wants to keep which is delivering magazines to distribution points. His wages range from $330 to $415 a month. That is over the $300 substantial gainful activity level of SSI. So his income, if he continues to work, is between $330 and $415 per month. The difficulty is that at that income level he losses his health insurance and since this is a part-time job, he cannot obtain private health insurance.

Under section 1619 you would think he would apply for section 1619 from Medicaid since that is what it was designed for. That is catch-22, since he is otherwise eligible for SSDI which he does not want, he is then ineligible for section 1619 and the health insurance he is otherwise entitled to.

So this young man, if he works, he receives no more than $415 a month with no health insurance; if he chooses not to work, he receives more than that, $500 a month from SSDI. This individual, if he is otherwise eligible for SSI but for DI eligibility can simply opt into section 1619.

Now there is a second reason why a person would want to opt into section 1619 other than level of earnings. I described that at page 5 of my testimony at the bottom of the page. This is an overgeneralization but while Medicare is generally a better plan than Medicaid, if you are disabled, that is not necessarily so. Medicaid does provide some medical services that provide greater independence for the physically or mentally disabled individuals such as attendant care to assist the disabled with related activities.

Those are attendant care which often is not available under Medicare. What this legislation would do is allow that person if it is better for him and thus better for the taxpayers to opt into SSI in section 1619, to do so. We have identified an additional set of barriers to work under this committee's jurisdiction which begin on page 6 of my testimony.

We would eliminate, for example, the 65 age limit eligibility requirement for section 1619(b) under SSI. How that requirement managed to creep into current law, I do not know. I remind the committee this only applies to those persons who are working and who choose to work. Under current law, once you reach age 65, you lose eligibility for section 1619(b) and thus are ineligible to continue to work and cost the taxpayers more money and have a lesser life for yourself.

We would eliminate spousal deeming so that it is only the person's income, not the spouse's that is considered for section 1619 eligibility. Currently, the Social Security Administration only counts personal attendant care when done in relation to specifically helping that person get ready to go to work in the morning, to get to work and while at work. But if the personal attendant care is used for grocery shopping or personal hygiene, then SSA attempts to split it and deduct it from the SSI benefit. This is purely an artificial distinction.

It is difficult to stay employed if you are not allowed to eat or shop or go to the grocery or take a bath or brush your teeth. We would negotiate to allow a person to retain the cost of living and to continue to retain the section 1619(b) Medicaid benefits. Again this is only for someone working for a living and who needs section 1619(b) to maintain health insurance. We would handle the royalty problem by treating any royalties earned by an SSI recipient by publication of a book as earned income so such income will not be deducted from the SSI benefit. The H.R. 8 compromise, which I expect to be introduced sometime this month in the Senate, will be presented to the Ways and Means Committee in the House.

Those other changes would create a special category of disabled and working. That will be handled by Mr. Jacobs' subcommittee. One last provision on page 9 of my testimony for this subcommittee, is the case of an individual who wrote to me to describe the difficulty which can be handled by what I suggest as automatic reinstatement to Medicare.

This will become an increasing problem as work incentive programs begin to work more often. That is the individual who is on SSI as this woman named Miss Bingham who lives in Texas, this person was and is eligible for SSI because of her disability. Because of section 1619, she went to work while retaining Medicaid. The problem is during her work experience she accrued DI eligibility, six quarters for that. Subsequently, her health condition and disability worsened and she was forced to leave her employment hopefully for a temporary period of time because of her disability itself.

In leaving her employment she expected to go back simply to SSI and Medicaid which she had previously been eligible for. But now because she has earned her way into DI eligibility she is forced into SSDI and that is Medicare. The problem here is there is a 2-year waiting period for Medicare. So at the very time that her health condition worsened, because she has worked for over six quarters, she losses access to her only form of health insurance.

I don't believe that is the intent of the law.

One last point and I will wind up and I appreciate the subcommittee's indulgence and putting these provisions into reconciliation. I will have an estimate from CBO on the cost, but I want to give you some rough estimates. We took out of H.R. 8 the most costly budgetary items and we left in the least costly. In doing that, we left in the ones with the highest impact on people who want to go back to work and took out the ones with the least impact.

My estimate, which is a rough one, based on verbal conversations with CBO, the cost for the Medicare buy-in, a total of $50 million over a 5-year period. The cost for the disabled adult children $18 million over 5 years. We still don't have an approximate cost estimate for the SSI opt-in by the SSDI beneficiary which is under the jurisdiction of this subcommittee.

It is my belief that this is such a small number of individuals, I expect the cost for this subcommittee will be less than the other two costs which are already in the negligible range. I know it is impossible to get the OMB or CBO to make any kind of a revenue impact and offset it against the cost but I want to bring to your attention what the revenue impact in a dynamic revenue estimate would be if CBO or OMB would do a revenue impact.

Consider we spend in cash benefits to SSDI beneficiaries $550 a month each. If one person is able to go back to work as a result of this, we would save $7,000. If 1,000 persons were able to go back to work and where there is a population pool of 2.8 million SSDI, if 1,000 were able to go back to work there would be a cost savings of $7 million. If as soon as 10,000 were to go back to work, it would have a revenue impact of $70 million to the good. It is my opinion that over the years by using this kind of device the impact on lives could be in excess of 10,000, more on the scale of 100,000 or more. So we have a large ability to improve our budget and help taxpayers at the same time as allowing people to go to work and help themselves.

Acting Chairman DOWNEY. Thank you, Jim.

[The statement of Hon. Steve Bartlett follows:]

TESTIMONY BY CONGRESSMAN STEVE BARTLETT
BEFORE THE SUBCOMMITTEE ON HUMAN RESOURCES
MAY 30, 1989

Mr. Chairman and Members of the Subcommittee, I appreciate the opportunity to testify before the Subcommittee today on the compromise to H.R. 8, the Social Security Work Incentives Act.

On January 3, 1989, Congressman Matsui, Congressman Levin and I, along with 94 original cosponsors introduced H.R. 8, the Social Security Work Incentives Act. Today, there are 176 cosponsors on this bill. This legislation is the follow-on to the 1619 program for SSI, and particularly the legislation of Public Law 99-643, the Employment Opportunities for Disabled Americans Act, which this Subcommittee helped enact in 1986. This law eliminates work disincentives for SSI recipients who want to accept a job without facing the risk of losing health insurance benefits. Since enactment of Public Law 99-643, the number of people on SSI with earnings has increased by 20,000 nationwide. In 1619(a), those receiving some cash benefits and Medicaid, participation has increased 1,387 percent since June, 1987 (the month before enactment) and in 1619(b), those receiving only Medicaid benefits, participation has increased 25 percent in the same time period. This data clearly reflects that enactment of this legislation has had a dramatic effect.

The good news is that 1619 has given SSI recipients an opportunity to attempt to work without losing health insurance benefits. The bad news is that this work incentive only applies to SSI recipients, not to SSDI recipients. The purpose of H.R. 8 is to extend that incentive to persons who participate in the SSDI program. Today, if you are on SSDI and you want to return to work, you lose all your cash benefits after the trial work period of 9 months and you lose all your Medicare health insurance benefits after 48 months. However, if you are on SSDI and stay unemployed, you receive Medicare.

Congressman Jacobs has been very instrumental in working out a compromise that will maintain the concepts of H.R. 8 while minimizing its impact on the budget. However, he cannot consider parts of the compromise that are not within his Subcommittee's jurisdiction. One part of that compromise will allow SSDI recipients the option to come under the SSI program after completion of the nine month trial work period when they are no longer receiving SSDI cash benefits because of earnings. These SSDI recipients could move into SSI and the Section 1619 work incentive program without first having a month of regular SSI benefits. This option would only apply to those individuals who meet the SSI income and resource test under current law. Such an option will allow SSDI recipients the opportunity to continue to work under 1619 in the SSI program.

Under current law, an individual who is receiving SSDI benefits at a low enough level to also qualify for SSI benefits, can, when their earnings disqualify them from SSDI cash benefits, remain eligible for SSI cash benefits and Medicaid. When SSDI cash benefits are lost, the SSI benefit increases to replace the lost SSDI benefits. For such individuals to have been concurrently eligible for SSI while receiving SSDI benefits, they must meet the other SSI eligibility requirements.

This proposal would treat SSDI recipients who lose their cash benefits in a manner similar to how concurrent SSDI/SSI recipients are treated under the present SSI and Section 1619 work incentive law when SSDI cash benefits are lost. Individuals who were ineligible for SSI cash benefits only because their SSDI benefit level was above the SSI benefit standard would move into SSI and Section 1619 eligibility status the first month after their SSDI cash benefits cease. The proposal would provide SSDI recipients who lose their cash benefits and whose impairment continues, but have resources

above the SSI resources limit, a period of time to spend down their resources. Such individuals would be placed in a suspension status for up to 33 months after SSDI cash benefits are lost due to earnings. This 33 month limit corresponds to the extended period of eligibility under current law.

Let me illustrate the problem under current law through a real life example of a constituent from Congressman Stark's district.

Harry is disabled. He has been receiving SSDI benefits of $570 per month. Since that is $10 above the SSI income limit, he is not eligible for SSI. He has a job delivering magazines to distribution points for a salary of between $303 to $415 per month. Since that is over the current $300 substantial gainful activity level (SGA) and he has exhausted his trial work period, his SSDI benefit will be terminated. Therefore, his income will only be $303 to $415 per month.

Since that is not enough to live on, Harry would be eligible to apply for the 1619 Program under SSI. This would allow him to continue his job and receive some SSI cash benefits and Medicaid. However, under current law, Harry can never apply for SSI because he is eligible for SSDI and since his SSDI benefit is above the SSI limit, he would never qualify for SSI. If his SSDI benefit was under the SSI limit, he would be eligible to apply for SSI and continue to work under the 1619 work incentive. Therefore, under current law, Harry has no incentive to work.

However, under our legislative proposal Harry could opt into the SSI program once his trial work period had ended, as it has. He would then be eligible to participate in 1619, receive Medicaid health benefits, and continue working.

This proposal addresses the current problem that many SSDI recipients face who have SSDI cash benefits just above the SSI benefit standard and who, in many cases, are very similar to SSI recipients. In addition, this proposal assists many mentally disabled SSDI recipients who must live with their parents or other family members. Many of these SSDI recipients do not qualify for SSI because the SSI law requires a one third reduction in their SSI benefit if they receive support from living in the household of another. Thus, while their income may be less than $250 per month, the individual cannot qualify for SSI due to the one third reduction rule and if they attempt to work they do not have the protection of the 1619 work incentive program.

Finally, this proposal provides Medicaid health benefits to SSDI recipients. While SSDI recipients receive Medicare after a two year waiting period, for many disabled, services provided by Medicaid may provide greater independence for the physically or mentally disabled individual, such as attendant care services to assist disabled individuals with employment related activities.

Such a change to the SSI law will encourage SSDI recipients who want to return to work that opportunity without losing health insurance benefits.

There are also several technical amendments to the 1619 program that we have proposed in H.R. 8 which I hope the Subcommittee will include in budget reconciliation. Some of these include:

Eliminating the 65 age limit eligibility requirement for 1619(b). Currently only disabled or blind individuals under age 65 are eligible to participate in the 1619(b) program which provides Medicaid benefits without cash benefits. There is not an age limit in 1619(a). The result is that individuals who were eligible for Medicaid on the basis of

1619(b), lose that Medicaid coverage once they turn 65 in spite of the fact that they are still eligible for SSI on the basis of their disability;

Eliminating spousal deeming in the 1619 program so that eligibility for 1619 is based on the SSI recipients' income alone, not on their spouse's income;

Including the full cost of personal attendant services when determining the threshold level for an individual under 1619(b). Currently, the Social Security Administration only counts personal attendant care when it is done in relation to helping the person get ready for work, get to work and while at work. If the personal attendant care is used for grocery shopping or personal hygiene, SSA counts such care as income and deducts it from the SSI benefit;

Allowing an SSI individual who receives a COLA which renders him ineligible for SSI to continue to retain 1619(b) Medicaid benefits; and,

Treating any royalties which are earned by an SSI recipient through publication of his work, scholarships, grants or fellowships as earned income so that such income will not be deducted from the SSI benefit.

These are technical changes that need to be made to the 1619 program in order to continue the smooth transition from unemployment to employment for SSI recipients.

These are the amendments in the H.R. 8 compromise that pertain to the SSI program and fall under the jurisdiction of this Subcommittee. However, this is a work incentive package that includes other provisions which must be considered by other Subcommittees. While each separate piece is important, I believe it is important for the Subcommittee to understand that the proposal will not be a work incentive unless all the pieces can come together into one package.

The H.R. 8 compromise would create a special category entitled "disabled and working" for disabled adult children when their earnings reach and exceed the $300 per month SGA level. Under this compromise, when a disabled adult child returns to work, regardless of whether his earnings would place him in the "disabled and working" status, his monthly benefit will be reduced $1 for every $2 earned, after exclusion of the first $85 and any impairment related work expenses. Thus, the cash benefit begins to phase out. This is both a savings to the government and it is also an incentive to the individual who is going back to work.

Since the real disincentive to returning to work is the risk of losing Medicare, this proposal provides a buy-in to the Medicare system for all SSDI recipients not just the disabled adult children in the "disabled and working" status. This buy-in would begin after the current 48 month period is exhausted. (9 months of trial work receiving full cash benefits and Medicare and 36 months of extended period of eligibility receiving only Medicare).

The rules of the buy-in are:

The State Medicaid Plan would pay the Medicare premium for individuals with earnings below 150 percent of the poverty level ($8970 in 1989);

For individuals with earnings between 150 percent and 300 percent of the poverty level, the State Medicaid Plan would pay a declining portion of the Medicare premium with the worker paying the balance; and,

For individuals earning over 300 percent of the poverty level, the worker would pay the entire Medicare premium himself ($17,940 in 1989).

Now that is expensive, but disabled workers who are working are not so concerned about the expense as the ability to be certain they have Medicare. We have also included a provision in this proposal that Medicare would be the secondary payor meaning that private health insurance or the employer group policy would be the payor of first resort and not the payor of last resort.

Finally with regard to the 1619 work incentive, a constituent of mine has informed me of a major disincentive that occurs when the disabled person begins contributing to social security insurance based on earnings from their own work record.

Ms. Bingham was working under the 1619 work incentive program and lost her job. Because she had worked over 6 quarters or a year and a half, she was now eligible for SSDI. The good news is the SSDI benefit is higher than what she received under SSI; the bad news is she must wait 2 years before she can receive Medicare benefits. Since she is no longer eligible for SSI she has no Medicaid benefits. Thus, because Ms. Bingham was successful at working for a period of time, she is penalized by losing access to health benefits for 2 years.

This problem will occur more and more as SSI recipients begin to work under the 1619 work incentive program and pay into the social security insurance program based on their own work record. Under current law, if an SSDI recipient is terminated from the rolls due to earnings, he has 5 years during which he can reapply for SSDI benefits as long as he has the same disability. If he applies within 5 years, the two year Medicare waiting period is waived. I recommend that a similar provision be adopted for those individuals, such as Ms. Bingham, who, but for losing their job, would still be eligible for Medicaid under the 1619 work incentive program.

In order for the H.R. 8 compromise to become law this year, I urge this Subcommittee to work with the Subcommittee on Social Security and the Subcommittee on Health so that a complete SSDI work incentive package can be included in budget reconciliation this year.

In 1987, 2.8 million disabled people received SSDI benefits and approximately 33 percent were under age 45. Under the present system, only one-half of 1 percent of these workers are returning to the work force. SSDI recipients under age 45 are in their prime working years and could contribute substantially to our economy if they could return to work. If this legislation can double that percent, it will be a tremendous success.

Finally, I would like to mention briefly another piece of legislation that Congressman Matsui and I introduced this year, H.R. 71, the Independent Living Trusts and Contributions Act. This legislation will allow parents and families to assist their disabled family member without jeopardizing that individual's eligibility for or amount of benefits under the SSI program.

I became aware of a problem in this area when parents in my Congressional District told me of their concern to provide for their disabled child once they have passed away. Currently, a disabled individual can lose SSI benefits along with health insurance benefits if they inherit from their parents. The disabled individual must "spend down" his inheritance before he can again become eligible for SSI benefits. During this period, the SSI recipient loses Medicaid benefits which are essential to the individual. The result has been that many parents have no other choice but to disinherit their disabled child so that these basic benefits will not be lost.

Many parents and families would like to assist their family members who have disabilities without that individual losing his eligibility for SSI benefits. These parents and families are only seeking to privately supplement SSI benefits; they are not seeking to obtain additional federal dollars for their family member. Rather, these parents and families seek an opportunity to use their own funds to assist the disabled individual without risking that person's basis of support. These parents and families want a clearer, more understandable, and reliable set of criteria for long term planning. This bill will provide that understanding.

Under H.R. 71, contributions from family members or others would not be counted as income for purposes of eligibility or benefit computation when those contributions are made to provide services in these areas: social services, vocational rehabilitation, private medical coverage, educational services, personal assistance or attendant care services, clothing, or subsidies for housing such as rent or mortgage payments. In addition, a family can create a trust to provide these same services and that trust will not be counted as an asset or as income to the SSI recipient.

Senator Dole and I are working with the Social Security Administration to try and work out legislation that reflects their current policy with regard to this issue. However, I wanted to bring this issue to the attention of the Subcommittee so that we can begin to work on a solution to this problem.

I thank the Subcommittee for this opportunity and will gladly answer any questions you may have.

STATEMENT OF HON. JIM SLATTERY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF KANSAS

Mr. SLATTERY. Thank you.

I appreciate the opportunity to testify before your panel today and discuss legislation I have introduced related to the disabled children of U.S. military personnel stationed overseas.

I first became aware of the need for this legislation in 1987 when I was contacted by a young couple stationed at Fort Riley, Kansas.

This couple has a young daughter, Vanessa, who has moderate cerebral palsy, which is complicated by several mildly disabling developmental conditions.

While living on the military base at Fort Riley, this family met the income standards and medical guidelines necessary to be eligible for supplemental security income benefits.

With these additional resources, Vanessa was able to receive the type of ongoing, individualized treatment necessary to slow the gradual deterioration associated with cerebral palsy and aggravated, in this case, by Vanessa's other conditions.

When Vanessa's father received orders to serve an overseas tour of duty in Germany, the family learned that they would be forced to forfeit their SSI eligibility while stationed outside the United States.

The loss of these resources occurs regardless of confirmed SSI eligibility and constitutes a significant sacrifice for families like Vanessa's that live on a limited income, but also face the ongoing, and often expensive, costs associated with caring for a disabled child.

The legislation before the committee today, H.R. 874, would relieve the financial and emotional burden placed on American families with special needs children, who serve our Nation in active duty overseas.

According to the U.S. Army Office of the Surgeon General, approximately 200 families now stationed abroad have relinquished their SSI eligibility.

These families face significantly increased financial burdens when they attempt to provide the same specialized care their children received while stationed in the States.

This loss is exacerbated by separation from relatives and friends who often provide additional emotional support and assistance in caring for a disabled child.

Overseas assignment, as you know, is considered an honor by many in the military.

Service abroad is also an important component to a successful military career.

The current system penalizes families with disabled children by either reducing their resources while they are stationed overseas or forcing families to remain in the States and endure extended separation from a parent who is on assignment in a foreign country.

Clearly, this situation creates a tremendous dilemma for military families with a disabled child.

The Congressional Budget Office estimates that this bill would cost less than $500,000 annually. Yet, enactment of H.R. 874 would allow several hundred young families to remain together and

would help to offset the ongoing costs associated with the specialized care and equipment required by a disabled child.

For Vanessa, this bill would mean that her parents could afford the weekly therapy and treatment that is critical to maintaining her health and preventing any additional deterioration in her condition.

For American families now living at military bases around the globe, enactment of H.R. 874 would mean that disabled and special needs children could continue to receive the adaptive equipment, medical attention and specialized care they urgently require.

H.R. 874 has received the endorsement of numerous national and international military organizations.

You will hear testimony today from a representative of the National Military Family Association on behalf of the many organizations supporting H.R. 874.

This representative has just returned from a tour of military bases in Germany where she conducted a series of meetings regarding H.R. 874 and other issues facing the families of American military personnel stationed overseas.

I believe the testimony of the NMFA will further illustrate the challenges facing military families with disabled children and the urgent need for enactment of H.R. 874.

In closing, I believe the strength of this Nation can be measured not only by our military might, but also in our expression of compassion and concern for the children and grandchildren who represent the future of this country.

I ask the subcommittee to support H.R. 874 and to ensure that this unique group of disabled children can continue to receive the type of specialized attention they require and deserve.

[The statement follows:]

STATEMENT OF

THE HONORABLE JIM SLATTERY

BEFORE THE
SUBCOMMITTEE ON HUMAN RESOURCES
OF THE
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES

MAY 30, 1989

Good afternoon, Mr. Chairman and Members of the Subcommittee. I am very pleased to be here today to discuss legislation I have authored to extend eligibility for Supplemental Security Income (SSI) to the disabled children of United States military stationed overseas.

I first became aware of the need for this legislation in 1987 when I was contacted by a young couple stationed at Ft. Riley, Kansas. This couple has a young daughter, Vanessa, who has moderate cerebral palsy, which is complicated by several other mildly disabling developmental conditions. While living on the military base at Ft. Riley, this family met the income standards and medical guidelines necessary to be eligible for Supplemental Security Income (SSI) benefits. With these additional resources, Vanessa was able to receive the type of ongoing, individualized treatment necessary to slow the gradual deterioration associated with cerebral palsy and aggravated, in this case, by Vanessa's other conditions.

When Vanessa's father received orders to serve an overseas tour of duty in Germany, the family learned that they would be forced to forfeit their SSI eligibility while stationed outside the United States. The loss of these resources occurs regardless of confirmed SSI eligibility and constitutes a significant sacrifice for families like Vanessa's that live on a limited income, but also face the ongoing, and often expensive, costs associated with caring for a disabled child.

The legislation before the committee today, H.R. 874, would relieve the financial and emotional burden placed on American families, with special needs children, who serve our nation in active duty overseas. According to the U.S. Army, Office of the Surgeon General, approximately 200 families now stationed abroad have relinquished their SSI eligibility. These families face significantly increased financial burdens when they attempt to provide the same specialized care their children received while stationed in the States. This loss is exacerbated by separation from relatives and friends who often provide additional emotional support and assistance in caring for a disabled child.

Overseas assignment is considered an honor by many in the military. Service abroad is also an important component to a successful military career. The current system penalizes families with disabled children by either reducing their resources while they are stationed overseas or forcing families to remain in the States and endure extended separation from a parent who is on assignment in a foreign country. Clearly, this situation creates a tremendous dilemma for military families with a disabled child.

The Congressional Budget Office estimates that this bill would cost less than $500,000 annually. Yet, enactment of H.R. 874 would allow several hundred young families to remain together and would help to offset the ongoing costs associated with the specialized care and equipment required by a disabled child. For Vanessa, this bill would mean that her parents could afford the weekly therapy and treatment that is critical to maintaining her health and preventing any additional deterioration in her condition. For American families now living at military bases around the globe, enactment of H.R. 874 would mean that disabled and special needs children could continue to receive the adaptive equipment, medical attention and specialized care they urgently require.

H.R. 874 has received the endorsement of numerous national and international military organizations. You will hear testimony today from a representative of the National Military Family Association (NMFA), on the behalf of the many organizations supporting H.R. 874. This representative has just returned from a tour of military bases in Germany where she conducted a series of meetings regarding H.R. 874 and other issues facing the families of American military personnel stationed overseas. I believe the testimony of the NMFA will further illustrate the challenges facing military families with disabled children and the urgent need for enactment of H.R. 874.

In closing, I believe the strength of this nation can be measured not only by our military might, but also in our expression of compassion and concern for the children and grandchildren who represent the future of this country. I ask the Subcommittee to support H.R. 874 and to ensure that this unique group of disabled children can continue to receive the type of specialized attention they require and deserve.

Acting Chairman DOWNEY. It is the subcommittee's intention to put some or all of your bills in its reconciliation markup. We are here to have you explain these provisions, all of which I find noteworthy.

Brian, can you give me a reason why someone might oppose your bill?

I can't think of any, but maybe you have heard of some.

Mr. DONNELLY. Hopefully, there aren't too many opponents of this measure.

Let me address the issue of cost, the main objection. I would like to say for the record that I disagree with the high estimate that has come from CBO, in the sense that only under the way we do our bizarre accounting on the Federal level could you assess hundreds of millions of dollars of cost to a situation where you are taking children out of an institution where clearly it is more expensive to care for them and you are putting that child in their home.

But understanding how we do account, I would say at this time we are not certain about those estimates.

I think the costs are substantially lower.

My staff is willing to work with the committee staff to see if we can put together a proposal to keep the costs down, but keep in the components of helping these families remain united.

When Mrs. Mulligan gives her testimony, you will see a situation where the Federal Government demands that families break up.

In order for that family, and most especially that child, to be eligible for quality medical care, I think it is something that we as an institution have an absolute responsibility to step in and change that absurd policy.

Acting Chairman DOWNEY. Steve, let me ask you a couple of questions about your legislation.

If someone earned less than they would be entitled to under SSI, would they be able to keep a small portion of their SSI check as well?

Mr. BARTLETT. Yes, we do have a sliding scale. They can earn up to $300 a month with no offset or if they earn more than that, the offset begins with $85 of the cash benefit.

This legislation was introduced this session and last session with a similar sliding scale of cash benefit offset. It was my conclusion that that portion of the bill was weighing it down. It was not a tremendous cost.

I agree with Brian, it was not a cost but rather a static accounting type of cost.

Rather than hold up the rest of the bill, we chose to handle the SSI–SSDI and handle the Medicare buy-in.

Acting Chairman DOWNEY. If this is good, why wouldn't it be good for welfare, too? Why wouldn't we want to provide a cost incentive for a mother on AFDC to do it, too?

Mr. BARTLETT. It would be good for welfare also.

I know this subcommittee needs to come to the next level of welfare reform, welfare reform 2.

Obviously you have to be aware of the woodworking phenomenon.

We don't want to set up a program to induce people to enter into a program who would otherwise stay off it.

In order to be eligible, you have to have a permanent impairment and disability.

In the disability legislation, we are dealing with people who have a medical impairment who are otherwise clearly eligible for the program if they choose not to work.

Acting Chairman DOWNEY. To the extent we can provide incentives to work for anyone, we should continue to do that.

The problem has been that if you are receiving a dollar or two of AFDC, you are labeled welfare dependent. I believe you should not be less well off working than staying home.

Mr. BARTLETT. In the case of AFDC or welfare, you would want to structure it more like a transition. Persons who have permanent disabilities, their earnings are often limited by their disabilities, but their earnings in no case should be limited to zero. It is only because of Federal law that their earnings get limited to zero.

Acting Chairman DOWNEY. We are going to look into this in conjunction with the Social Security Subcommittee as well.

Jim, what about helping other Federal employees that are stationed overseas, say, working for the State Department?

Could you see covering them in your proposal?

Mr. SLATTERY. Good idea.

I think that just because someone is stationed overseas whether they are working for the Foreign Service or the U.S. Army, it seems to me they should be treated the same and we should not put families that happen to have disabled children in a very discriminatory position vis-a-vis their other employees in the job marketplace.

I think they all should be treated the same.

Acting Chairman DOWNEY. We want to work with you on this.

I was speaking with the staff a minute ago. The Department of Defense says this problem does not exist. It is one of many problems I suspect they feel does not exist.

Mr. SLATTERY. The testimony you will hear today from the representative of the National Military Family Association will refute a lot of what you may have heard from the Pentagon.

This representative has just returned from Germany where she has had an opportunity to visit with over 1,000 families.

It will be interesting to hear her testify, which I think will shed more light on this whole question.

Mr. Ford.

Mr. FORD. Jim, are you suggesting in your legislation that the supplementals be employed for disabled children of military personnel?

Mr. SLATTERY. Those who are stationed overseas.

If someone is a member of the First Division stationed at Fort Riley, Kansas, if they are eligible to receive SSI benefits, the child, not the parent, is eligible, they can do that, but if they move overseas, they lose the SSI eligibility for the disabled child when they move overseas.

This legislation would address that very problem.

Just because that family is stationed overseas, they would not lose their SSI eligibility for their disabled child.

Mr. FORD. You indicated in your testimony that the computation is about 200 families; correct?

Mr. SLATTERY. We are looking at only about 200 families, but this is a major problem for 200 families who are currently serving our Nation in the military service.

Mr. FORD. The chairman indicated that he is almost certain that the amendments and bills we're talking about today will probably be included in the markup session.

Where did you get your cost figures on this?

Mr. SLATTERY. This is a CBO estimate.

Mr. FORD. If it agrees with the chairman's mark, three distinguished colleagues and one who serves on the Ways and Means Committee, would you comment on whether or not either of the three would support any increases in SSI benefits in general to the SSI recipients now receiving benefits?

Mr. DONNELLY. I would be happy to comment on that as a member of the full committee.

The answer is clearly yes.

I also stated in my testimony that I personally will be more than willing to find some revenue source that would be necessary to pay for this type of legislation and the broadening of benefits in general.

I am committed to work with the subcommittee and full committee and the staff as we go through the reconciliation process.

My answer is a resounding yes, Mr. Ford.

Mr. SLATTERY. A short answer is yes.

SSI is a means-tested entitlement program. When you talk about SSI, you are talking about the most needy in our society.

We should view means-tested entitlements differently than we do other nonmeans tested entitlements if we ever hope to get our budget under control.

Let's talk about helping the needy in our society, and to do that, we might have to address the method of computing future increases in other nonmeans tested entitlements.

Those are the choices we will have to make if we ever hope to get our budget in control.

Mr. BARTLETT. Mr. Ford, you were the original sponsor of the section 1619 bill which resulted in 18 short months of 20,000 individuals leaving the unemployment rolls and going onto the employed rolls.

I cannot give you a categorical yes or no as far as increasing SSI benefits.

I would look at it like any other Member. My general approach has been to find ways to remove barriers in SSI and SSDI that keep people from working, people who want to go to work, whose employers want them to work and who are kept from working by the Federal laws.

I don't see SSDI as higher or lower benefits. I see it as removing benefits so people can go to work on their own.

They are better off. The economy is better off, and the taxpayers are better off because we actually lower the aggregate amount of benefits while keeping the benefits per person the same.

I understand your point that perhaps there are ways where SSI should be increased in individual cases.

I focus more on how you allow people to go to work.

Mr. FORD. I didn't want to put either of you on the spot about this increase in SSI. The last time we worked in this area we saw that the benefit levels were very low. It might be that this committee will report to the House some type of benefit increases in SSI—we have also passed the welfare reform package.

One of the provisions the chairman referred to is the welfare package where those who receive benefits and want to go into the work force can.

The past administration wanted to cut out the work provision in the welfare package.

Another question you raised here, was that dealing with handicapped, the blind, and disabled.

What percentage or do you have any numbers, Mr. Bartlett, as to how many of these people could, in fact, go into the work force and maintain some type of gainful employment.

Mr. BARTLETT. We have various numbers. No one knows the exact number.

The Lou Harris survey concluded that of the 2.8 million SSDI recipients and there is also 1.7 million SSI disabled recipients that some 70 to 80 percent want to go back to work, technology will allow them to go back to work.

So of those 3 to 4 million Americans receiving disability payments by the Federal Government, perhaps as many as 3 million of them would go back into the work force if permitted to do so.

When Lou Harris asked what is the principal barrier to go back to work, no one answered it was low benefits from SSI or SSDI.

Seventy percent answered it was lack of health insurance.

Mr. FORD. It is not just health insurance. I had a handicapped person work in my district office over a 5-year period who had real problems coming in to the work force and no longer being eligible for benefits, not just health care benefits.

I understand your plight. I understand what you are trying to accomplish.

I have had personal experience in my office staff with situations like this.

Thank you, Mr. Chairman.

Acting Chairman DOWNEY. That was a good question put to the three of you because the subcommittee contemplates an increase for all SSI recipients and will contemplate an increase in SSI every year either one of us is a member of the subcommittee.

SSI benefits are means tested and significantly below poverty. We do add food stamps, but for those who cannot work, it is a difficult and painful experience and we will try to make it easier.

Mr. DONNELLY. Mr. Chairman, you have my proxy.

Acting Chairman DOWNEY. Thank you.

STATEMENT OF LOUIS D. ENOFF, DEPUTY COMMISSIONER FOR PROGRAMS, SOCIAL SECURITY ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY RHODA M.G. DAVIS, ASSOCIATE COMMISSIONER FOR SUPPLEMENTAL SECURITY INCOME

Mr. ENOFF. Mr. Chairman, you have my complete statement which I will provide for the record.

Acting Chairman DOWNEY. Without objection, it will be included in the record.

Mr. ENOFF. I am pleased to be here to talk about the supplemental security income [SSI] program today and some of our outreach efforts. My prepared statement addresses in detail all the issues about which you have expressed interest.

With your permission, I would like to submit my longer, prepared statement for the record and limit my oral remarks to the areas of outreach efforts and issues related to disabled children.

We have a commitment to outreach which we have tried to expand over the years. We reported on many of our outreach activities at the March 2, 1989, joint hearing before this subcommittee and the Select Committee on Aging, so I will not repeat them here.

I would, however, like to tell you about an upcoming event that will improve our ability to reach out effectively—something that we are very enthusiastic about.

Commissioner Hardy has invited some 50 service and advocacy organizations to a symposium on outreach to be held June 14. The symposium will permit us to discuss with these organizations what we know mutually about communicating with people who might be eligible for SSI and how best to help them in the application process.

Our objective will be to come away with a plan of coordinated and collaborative activities that can be tested and implemented at both the national and local levels.

There are many, very different segments of the potentially eligible population. While we have ideas on how to reach them, we want to hear from the service and advocacy organizations concerning their ideas.

We want to pool their talents, resources and innovative ideas with ours to help us to determine the best way to communicate with parents of disabled youngsters, reach out to the aged living alone with dwindling life savings, and locate young people with chronic mental illness, and to develop these strategies for urban and rural settings.

The effectiveness of outreach efforts, in large part, depends on having the flexibility to explore and develop a variety of approaches targeted at specific groups.

Legislation which specifies outreach methods could result in the required use of resources for less effective methods than otherwise might be employed. Thus, it would be inappropriate to mandate specific administrative activities by law.

Now, I would like to talk about disabled children under SSI. A child is considered disabled for SSI purposes if he suffers from any medically determinable physical or mental impairment of compara-

ble severity to that which would be considered disabling for an adult. As with an adult, a child must have an impairment which is expected to result in death or last at least 12 months. Also as with an adult, the child is presumed to be disabled if his impairment or combination of impairments meets or equals one of the listed impairments.

Unlike adult worker claimants, however, children are not evaluated on whether their impairments or combination of impairments prevent them from working because they have not had any attachment to the workforce.

However, children are covered by special listings in the regulations. These listings were developed because the criteria for adults do not always give appropriate consideration to the particular effects of certain disease processes in children. They were formulated at the outset of the SSI program after extensive study and consultation with experts in pediatrics as well as other medical specialists. The criteria in the listings were designed to permit a determination of disability in children at a severity level comparable to that for which adults would be determined disabled.

If the child does not have an impairment that meets one of the listings, an individualized assessment of the child's physical or mental limitations is made to determine whether the impairment or combination of impairments equals the level of severity of the listings.

We believe that our approach to evaluating childhood disability claims is generally reasonable and that it satisfies the intent of Congress when it included disabled children under the SSI program.

To ensure that the childhood criteria do identify those children who are disabled and that the criteria are being properly applied, we are conducting a study of a sample of recently disallowed children's disability claims. If the study shows that the evaluation criteria for children need to be revised or expanded, or that additional training may be needed to ensure uniform application of the criteria, we will initiate appropriate actions to do so.

This concludes my statement, Mr. Chairman. I would be happy to answer any questions.

[The statement of Mr. Enoff follows:]

STATEMENT OF LOUIS D. ENOFF, DEPUTY COMMISSIONER FOR PROGRAMS, SOCIAL SECURITY ADMINISTRATION

I am pleased to be here to talk to you about the Supplemental Security Income (SSI) program issues in which you have expressed interest. In my remarks, I will tell you about our current efforts to locate and assist potentially eligible people (including disabled and blind children) to apply for SSI benefits and to give you some idea of the direction of our future outreach efforts. Next, I will review with you why disabled children are included under the SSI program, explain how the disability decisionmaking process works with regard to very young children, and talk briefly about whether a special $30 payment should be made to certain of these children. Finally, I will address specific SSI issues relating to living arrangements, extra monthly earnings, and benefit and resource levels.

OUTREACH EFFORTS

I will begin with a discussion of our outreach activities.

Our local Social Security offices provide the foundation of our longstanding, ongoing commitment to outreach. Local offices work with organizations in their service areas to help people learn about their potential eligibility for benefits under programs we administer.

SSA offices which have service areas with large non-English speaking populations have staff who can translate or make arrangements with community organizations that can provide translators.

Our local offices maintain ongoing working relationships with institutions to help people apply for or restart benefits when they are discharged. These relationships are an important component of our ongoing outreach efforts. A recent initiative to help SSI claimants and former recipients make the transition from institutions to local communities has almost doubled the number of prerelease agreements our local offices have entered into with hospitals, nursing homes, mental institutions, prisons, and other facilities. These agreements allow for an early determination or redetermination of SSI eligibility for people who are institutionalized but are soon to be released to live in the community. Many of these people whose release is imminent do not have enough money to take care of themselves once they are on their own. If they wait until they are released to apply for SSI, or to seek to have their benefits restarted, they may be out and without funds while waiting for their eligibility to be established. In many cases that might result in homelessness.

To enhance the day-to-day outreach efforts carried on in the field, we are continuing our efforts on the national level to improve and expand SSI public information activities. Our efforts are focused in several directions, one of the most important of which is to maintain liaison with national, State, and local legal and welfare agencies and advocacy groups to tell them about the SSI program and enlist their assistance in finding potentially eligible people. Our outreach support efforts on the national level have included:

- providing field components with model presentations and a supporting universal slide series so they can tailor speeches about the SSI program to the needs of outside organizations;
- providing field components with monthly public information packages containing information about the SSI program (packages include news releases and scripts for radio and TV spot announcements suitable for local media use in Spanish and English);

- sending organizations with an interest in the SSI program the quarterly SSI Information Item Newsletter containing articles for them to publish in their own newsletters and bulletins;

- redesigning and revising publications and other printed materials for current and potential recipients to incorporate improved graphic techniques and to simplify the language; and

- preparing and distributing posters explaining basic SSI eligibility requirements (these posters have been placed in 39,000 post offices nationwide as well as in the offices of organizations that provide services to low-income aged, blind, and disabled people).

In recent times, we have been placing special emphasis on our service with regard to the homeless. Our homeless outreach efforts include:

- appointing a coordinator in each field office where such a position would be appropriate to act as the focal point for all claims and postentitlement activities relating to the homeless;

- encouraging district and branch managers or other appropriate field office staff to serve on interagency health and welfare councils serving the needs of the homeless;

- assuring that local staff "network" with private nonprofit community and religious organizations serving the needs of the homeless;

- assuring that individuals are aware of the relatively new provision for continued receipt of full SSI benefits for certain individuals temporarily institutionalized in public or private medical facilities;

- reminding shelter staffs about the SSI provision that permits continued receipt of SSI benefits for 6 months in any 9-consecutive-month period for persons who are residents of public emergency shelters for the homeless; and

- assuring that individuals are aware that there is no offset against SSI benefits because of receipt of charitable gifts based on need, from nonprofit organizations, of items such as meals from soup kitchens, clothing, and shelter.

In addition, we are preparing a series of "best practices" issuances which describe projects dealing with the homeless and other categories of hard-to-reach people which are working well in one setting and have potential for proving successful in another. These issuances should allow our offices and other service providers to give active consideration to practices that have already been proven in other areas.

We are also developing a videotape for providers of service; such as, social workers, shelter operators, etc., and our field staff to assist the service providers in understanding SSI eligibility requirements and the way we take and process claims.

Outreach to Disabled Children

Our current outreach effort to disabled children parallels that for other individuals eligible for the program. Our local offices maintain contacts with special schools for disabled children like the William J. Baer School in Baltimore and the Rainier School in Washington State to assure that individuals who might qualify for SSI apply and have their eligibility determined. They also work with the more general population of children to seek out the disabled among them. An example of this

is the outreach effort made through the Bessemer, Alabama, school system to assure that the parents of mentally retarded children in the school system are aware of their children's potential eligibility.

On the national level, we maintain contacts with diverse groups and organizations in an effort to reach all segments of the population. Through these contacts, these groups tell us how our programs are affecting the people they represent and we are able to give them the kinds of specific information about our programs that they need in order to help their constituents. In this way, groups such as the Down Syndrome Congress and the Association of Retarded Citizens receive information about the availability of SSI benefits for disabled children.

American Association of Retired Persons' (AARP) SSI Outreach Project

Under a grant from the Commonwealth Fund, the AARP conducted an SSI outreach demonstration project last year designed to increase participation in the program. SSA, along with the Administration on Aging, cooperated with the AARP in its efforts to seek out and enroll aged persons who are eligible for, but not receiving, SSI benefits.

The outreach demonstrations took place in Pittsburgh, El Paso, and Oklahoma City. Each project was cosponsored by the local area agency on aging with assistance from senior centers, local nutrition programs, hospitals, and a variety of community service groups. Our field offices also cooperated with local area agencies on aging in the outreach demonstrations.

SSA actively participated on AARP's Technical Advisory Committee, as well as in the local SSI "coalitions" in El Paso, Oklahoma City, and Pittsburgh. We contributed to the demonstration project design, provided critical information on site selection, trained outreach workers, and provided data necessary to evaluate the project.

The AARP's final report on last year's demonstration outreach project indicates that its effort produced a substantial increase in both SSI applications and awards of benefits. Although this first phase provided no clear indication of the magnitude of the unreached population, it did establish that the type of outreach activities used should be pursued further in an effort to make SSI benefits available to as high a percentage of the eligible population as possible. Because of our interest in pursuing these outreach techniques, we are cosponsoring the AARP demonstration project in Rutland, Vermont, this year and actively participating in projects at the other nine sites that the AARP has included in the second year of its SSI outreach project.

Special SSI Outreach Efforts

The Social Security Amendments of 1983 required ongoing outreach activity to potential Social Security beneficiaries at the time they were notified of their upcoming eligibility for Supplementary Medical Insurance under Medicare at age 65.

Since July 1983, each month approximately 110,000 potential beneficiaries have been notified about the SSI program and its eligibility requirements at the time they receive notification of eligibility for Medicare.

It is estimated that the ongoing outreach effort has resulted in about 2,000 SSI awards to the elderly per month since July 1983, when the provision became effective. This is almost 2 percent of the 110,000 notices sent each month.

Our experience with outreach efforts--such as the ongoing monthly mailing to people nearing age 65 and a one-time "SSI Alert" provided for in the 1983 amendments--which are based on a match of large numbers of administrative records with only limited screening criteria is that these methods have limited effectiveness in locating potential SSI recipients. This experience and the knowledge gained from use of other outreach strategies lead us to believe that the use of administrative records does not warrant repetition. We believe that our resources should be used to develop more effective outreach strategies.

Planning for Future Outreach--The Commissioner's Initiative

After 15 years of experience in administering the SSI program, we have learned a great deal from the many national and local initiatives undertaken by us and others to inform people about their potential eligibility. We know that it is an effort that must be continually renewed and must involve a wide universe of individuals and groups outside of SSA.

I am very pleased to be able to report that, in recognition of the need for renewed outreach efforts and the challenges of such a effort, Commissioner Hardy has invited some 50 service and advocacy organizations to a symposium on outreach to be held June 14. The symposium will permit us to discuss with these organizations what we know mutually about communicating with people who might be eligible for SSI and how best to help them in the application process. Our objective will be to come away with a plan of coordinated and collaborative activities that can be tested or implemented at both the national and local levels.

We are approaching the symposium and the activities that will follow it with enthusiasm. There are many, very different segments of the potentially eligible population. While we have ideas on how to reach them, we want to hear from the service and advocacy organizations concerning their ideas. We want to pool their talents, resources, and innovative ideas with ours to help us to determine the best way to communicate with parents of disabled youngsters, to reach out to the aged living alone with dwindling life savings, or to locate young people with chronic mental illness, and to develop these strategies for urban and rural settings.

The effectiveness of outreach efforts, in large part, depends on having the flexibility to explore and develop a variety of approaches targeted at specific groups. Legislation which specifies outreach methods could result in the required use of resources in the continuation of less effective methods than otherwise might be employed. In light of the ongoing outreach activities we are already pursuing and the additional efforts which will begin shortly after the June 14 symposium, it would be inappropriate to mandate specific administrative activities by law.

DISABLED CHILDREN UNDER THE SSI PROGRAM

I will now move to a discussion of issues relating to disabled children in SSI.

When the Congress established the SSI program in 1972, it included disabled children under the program. The reason for doing so, expressed in the legislative history accompanying the legislation, was that disabled children living in low-income households are among the most disadvantaged of all Americans and deserving of special assistance to help them become self-supporting members of society. The intent was to provide disabled children living in low-income households, and within the

program's income and resource eligibility criteria, the advantage of eligibility for the SSI program, as well as benefit amounts generally exceeding those provided under State Aid to Families Dependent Children programs. This was viewed as appropriate because the needs of disabled children were believed to be greater than those of nondisabled children.

SSI Criteria for Disability

The SSI program has the same definition of disability as the Social Security disability insurance program. That is, the law requires that to be considered disabled, an adult must be unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last at least 12 months. This determination must be made on the basis of medically acceptable clinical and laboratory diagnostic techniques.

The determination of disability for an adult worker is done through a sequential evaluation process. An adult worker will be found disabled if he is not engaging in substantial gainful activity and has one of the impairments in Part A of the Listing of Impairments in the regulations or if the severity of his impairment or combination of impairments equals the level of severity of an impairment listed in Part A.

If the worker cannot be found disabled on the basis of medical factors alone, a determination of residual functional capacity is made to determine what the individual can still do. If past work is precluded, the individual's residual functional capacity is considered along with the vocational factors of age, education, and work experience to determine if he could be expected to perform other substantial gainful work that exists in the national economy.

Determining That a Child Is Disabled for SSI Payments

A child is considered disabled for SSI purposes if he suffers from any medically determinable physical or mental impairment of comparable severity to that which would be considered disabling for an adult. As with an adult, a child must have an impairment which is expected to result in death or last at least 12 months. Also as with an adult, the child is presumed to be disabled if his impairment or combination of impairments meets or equals one of the listed impairments.

Unlike adult worker claimants, however, children are not evaluated on whether their impairments or combination of impairments prevents them from performing past work or any other substantial gainful work which exists in the national economy. These evaluation steps, which were designed to take into account an individual's ability to perform work, are not applicable to children, who usually have not had any attachment to the workforce.

However, children are covered by the additional listings in Part B of the regulations. These special childhood listings were developed at the outset of the SSI program because the criteria in Part A do not always give appropriate consideration to the particular effects of certain disease processes in children. The listings were formulated after extensive study and consultation with experts in pediatrics as well as other medical specialists. In developing the listings, the experts considered the effects of physical and mental impairments on children as well as the impact of the impairments on children's activities and restrictions on growth, learning, and development imposed by the impairments.

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The criteria in the listings were designed to permit a determination of disability in children at a severity level "comparable" to that for which adults would be determined disabled.

In conjunction with a scheduled review of each body system in the listings, Part B (childhood) listings are receiving special review to ensure that the listings contain appropriate criteria.

Medical Equivalence

If the child does not qualify for benefits on the basis that he has an impairment that meets one of the listings, an individualized assessment of the child's physical or mental limitations is made to determine whether the impairment or combination of impairments equals the level of severity of the listings. This assessment involves a complex medical analysis of the various impairment findings, including all the signs, symptoms, and laboratory findings, to evaluate any functional limitations or restrictions on appropriate skills and activities and to compare such findings to the criteria of a given listed impairment.

Childhood Disability Awards

We believe that our approach for evaluating childhood disability claims is reasonable and that it satisfies the intent of Congress when it included disabled children under the SSI program. The number of disabled children receiving SSI benefits has more than doubled since 1975. In that year, 107,026 children received SSI. This number represented about 5.3 percent of all disabled SSI recipients. By 1987, this number had grown to 290,256 child disability recipients, representing almost 9.6 percent of all disabled SSI recipients.

Childhood Disability Study

We share the concern that all children should receive the SSI benefits to which they are entitled. To ensure that the childhood criteria do identify those children who are disabled and that the criteria are being properly applied, we are conducting a study of a sample of recently disallowed SSI disability claims. If the study shows that the evaluation criteria for children need to be revised or expanded, or that additional training may be needed to ensure uniform application of the criteria, we will initiate appropriate actions to do so.

Presumptive Disability for Children Under Age 4

Proposals have been made that would establish a presumption of disability for any child under age 4 born with certain genetic or congenital conditions. We strongly believe that such proposals would establish an undesirable precedent. A young child would be presumed to be disabled for SSI disability benefits on the basis of a diagnosis alone without evidence of the signs, symptoms, and laboratory findings to establish a severe impairment at the time his claim is evaluated. Because of the variability in the degree of impairment severity manifested during infancy and early childhood, we do not think it is clinically supportable to infer disability at birth on the basis of a diagnosis alone.

We have some further question as to the extent to which the primary purpose of such proposals may be to enable the children in question to qualify for Medicaid or other special health benefits. Thus, such proposals have both policy and cost implications that may go well beyond the SSI program *per se*.

Special Payments to Disabled Children Living at Home

A question has been raised about the appropriateness of providing an SSI cash benefit of up to $30 a month for certain disabled children who require the level of care that is usually provided in a hospital or skilled nursing facility but who can be cared for less expensively at home regardless of their parents' ability to take care of their needs for food, clothing, or shelter from the parents' income and resources.

The purpose of such a payment appears to be two-fold. The first is to provide a small amount of monthly income to meet incidental needs of the disabled child, since that is the reason that the SSI program provides a similar amount of assistance to individuals who are in institutions where Medicaid is the principal provider of both medical and basic needs. The other purpose appears to be the more important. It is to assure that the disabled child is eligible for Medicaid while living at home.

The proposal would have the effect of providing Medicaid eligibility in those States whose Medicaid plans use SSI eligibility criteria. However, it would not necessarily provide Medicaid reimbursement for the services the child would need to remain in the home. States have flexibility in the design of their programs. Twenty States and the District of Columbia have elected to cover such in-home medical care and services under an option that is currently available under Medicaid law, while the others have chosen to direct the resources to other needs, such as prenatal care and preventive care for children.

In addition, disabled children should not be made eligible for cash assistance benefits regardless of their parents' ability to provide for their support. This would seriously undercut the basic purpose of the SSI program for a reason that is not directly related to SSI's role as income maintenance program. The Medicaid program currently allows States to target coverage of medical and home health care to disabled children who are at risk of institutional care.

OTHER SSI ISSUES

Mr. Chairman, your press release also indicated your committee's interest in a number of other SSI issues having to do with living arrangements and the treatment of in-kind support and maintenance, the treatment of earnings when there are extra paydays in a month, and the benefit and resource levels under the SSI program. Each of these issues has been and is currently the subject of proposed amendments. I would like to comment now on these issues in that order.

Living Arrangements and the One-Third Reduction

Because the SSI program is means tested, all income in cash or in kind that is available to meet the individual's needs for food, clothing, and shelter, unless specifically excluded by statute, must be taken into account in determining whether cash assistance is needed to bring the individual's income level up to the SSI standard.

When people live with others and receive in-kind support and maintenance from them, the law provides that an amount equal to one-third of the Federal SSI benefit standard will be counted as income for eligibility and benefit purposes rather than the actual value of the in-kind support and maintenance received. The imputation of income equal to one-third of the SSI benefit was intended by Congress as a means to avoid the administrative difficulty of determining the actual value of in-kind support and maintenance.

Over the years, challenges to the one-third reduction have led to a complex set of policies that permit individuals to rebut the one-third reduction policy by showing that they pay partially or fully for the in-kind support and maintenance they receive from others. The application of the one-third reduction has also affected the way we treat all in-kind support and maintenance.

A proposal is pending that would change current policy by requiring the counting of the lesser of the actual amount of in-kind support and maintenance received from any source or an amount equal to one-third the SSI benefit standard. Another proposal would allow people not to be subject to the one-third reduction who, once they begin receiving SSI benefits, may be expected to pay a reasonable portion of the expenses of the households in which they live provided that that portion did not exceed an amount equivalent to two-thirds of the SSI benefit standard.

These proposals would make what are primarily technical adjustments in current policy, but they create equity problems and add significantly to the task of administering the program. We would recommend that no changes be made in current policy until better ways have been identified to deal with the whole body of policies surrounding living arrangements and in-kind support and maintenance. What is needed is a much simpler and less error-prone process which at the same time continues to provide equity of treatment and does not increase costs.

Treatment of Earnings When There Is an Extra Payday in a Month

You also expressed interest in the effect on SSI eligibility of wages when there are extra paydays in a month. Under current law, the income actually received in a month must be used to determine whether an individual is eligible for SSI in that same month. Generally, income received in the second month preceding the month for which the benefit is due is used to determine the amount of the SSI benefit payable. Individuals who receive income on a regular weekly or biweekly basis may receive extra amounts of income in some months because some months will have three or five rather than two or four paydays. The extra income may cause the individual to lose SSI and Medicaid eligibility based on SSI for a month.

It has been suggested that the law be amended to permit the continuation of an individual's SSI eligibility when he receives income on a regular weekly or biweekly basis that otherwise would make him ineligible for SSI benefits for that month if this income, when annualized and equally allocated on a monthly basis, would not cause the individual to be ineligible for benefits.

The suggested proposal would tend to undercut the basic purpose of the SSI program, which is to provide benefits to supplement the incomes of people up to the federally established SSI level. It would also be inequitable because it would provide special treatment for a certain, small group of recipients by permitting them to remain eligible for SSI when others with the same amount of monthly income would be ineligible. Because of the requirement to annualize and average earnings for those months when SSI would otherwise be lost, the proposal would add significantly to the complexity to the SSI program. The only purpose of such a proposal appears to be the preservation of individual's Medicaid eligibility, but the achievement of this end through a distortion of the SSI program does not seem justified.

We would oppose such a change for all of these reasons.

INCOME AND RESOURCE LEVELS

Proposals have been made to increase SSI benefit levels to the poverty line for one- and two-person households. It has also been proposed that SSI resource limits be increased to take into account increases in the cost of living that have occurred since the SSI program began in 1974 and to continue to index these limits to future cost-of-living increases.

Income Levels

Since the beginning of the SSI program, there has been discussion about the adequacy or inadequacy of the Federal benefit standard. The SSI benefit levels for an individual and for an eligible couple have been around 75 and 89 percent of the poverty line for one- or two-person households, respectively, since the program began in 1974. The effect of the exclusion from income of $20 a month of any unearned income the recipient gets has the effect of narrowing the difference between the SSI benefit levels and the poverty line by about 4 percentage points.

State supplementary benefit amounts further close the gap. In three States--Alaska, California, and Connecticut--SSI and State supplementary benefits provide income levels above the poverty line for one-person households. Eight States--the three that have already been named and Colorado, Massachusetts, Oklahoma, Rhode Island, and Wisconsin--provide supplements to SSI for eligible couples that raise income levels to above the poverty line for two-person households.

Also, of course, benefits under other Federal programs are available to SSI recipients. For example, when the value of food stamps is added to the basic Federal benefit standard, the recipient's effective purchasing power is substantially increased. Using the 1989 poverty guidelines and SSI benefit levels, an individual who has a small Social Security benefit and is also eligible for SSI in a State that does not offer any supplementary benefits has total cash income of $388 a month in 1989. Based on that level of income, the individual can get food stamps with a value of between $10 and $90 a month. His total income would then be between 80 and 96 percent of the poverty guidelines. An eligible couple, in the same circumstances, would have total cash benefits of $573 a month plus between $25 and $165 a month under the Thrifty Food Plan. The couple's total income would range between 90 and 110 percent of the poverty guidelines.

SSI recipients also are categorically eligible for Medicaid in most States. While this coverage does not provide assistance in meeting normal daily needs, it does reduce or prevent the need to use scarce income and resources to obtain health care. Energy assistance under the Low Income Home Energy Assistance Program and low-income housing and rent subsidies under Federal housing assistance programs are other sources of assistance that help make the cash assistance go further toward meeting basic needs for some people.

In conclusion, we believe that the current SSI benefit levels bear an appropriate relationship to the poverty line when other assistance, such as State supplementation, food stamps, Medicaid, and Federal housing assistance that is available to many SSI-eligible individuals, is taken into account.

Resource Levels

The SSI resource test is one of the eligibility requirements designed to measure an individual's need for SSI assistance. In setting such an eligibility requirement for a cash assistance program like SSI which is funded by general revenues, it is

reasonable to expect people to use their own assets to meet day-to-day expenses before the Federal Government is asked to provide them with income assistance. However, it is recognized that people need to have a certain level of assets to provide for emergencies or other unusual or nonrecurring expenses that cannot be met from the basic monthly benefits.

SSI law sets limits on the value of resources a person can own and still be eligible for SSI. In determining the amount of resources that are counted, only the amount of resources that represents the individual's equity is considered.

Although the law does not state what a resource is, it does provide that, in determining whether an individual's resources are within eligibility limits, the value of certain resources will be wholly or partially excluded from countable resources. When the exclusions from resources are taken into account, the resource levels above which SSI eligibility is precluded are not so limiting as the dollar amounts might suggest. The value of things that most people own that are related to basic needs is not counted toward the limits (i.e., a home, household furnishings, personal effects, and a car). In addition, life insurance, property essential for self-support, burial plots, and funds set aside for burial are excluded within certain limits.

In reality, an individual can own resources of considerable value and still be eligible for SSI. For example, a person's total net worth could be $110,000 (home, $100,000; automobile, $4,500; personal effects and household goods equity value, $2,000; burial fund, $1,500; savings, $2,000) and he could still be eligible for SSI. In most cases, when a recipient's resources cause ineligibility for SSI it is because the value of bank accounts and nonexcluded real property exceed the resource limits.

Since so many of the things people own that are necessary to daily living (the home, personal effects, household goods, an automobile, etc.) are excluded as resources, the primary effect of raising resource limits would be to permit individuals with relatively large cash reserves to retain those while receiving publicly funded assistance. Because of this effect, we do not think that increases in the SSI resource limits are justified.

In addition, increases in the SSI assets limits would result in poor targeting of public assistance monies. Increases in the resource levels will help only those whose financial situation now prevents or delays their becoming eligible for public assistance. It will not improve the economic condition of the majority of those already receiving benefits, most of whom have very little in resources. In fact, only about 7 percent of aged recipients had resources of $1,500 in 1986, when the limit was $1,700. Further, the higher the level, the greater becomes the question of the appropriateness of providing publicly funded assistance to people who have the means to provide for themselves.

CONCLUSION

This concludes my statement Mr. Chairman. I would be happy to answer any questions.

Acting Chairman DOWNEY. At the hearing in March, you mentioned your outreach efforts. I am delighted to know this symposium is being held and there will be a massive effort to let people know, at least in a one-shot way, of their potential eligibility for SSI. Are you planning any additional efforts other than the ones you already have scheduled to inform persons who might be eligible?

I am sure it is important to make a bold, massive attempt, but that is not enough. We have to do more in terms of finding the people who are eligible and make them aware of their eligibility.

Mr. ENOFF. We are making efforts. We have done many things since the March 2 hearings. Our intention is to work with the advocacy groups and inform them about the difficulties we are finding.

I think the activities that have taken place have shown that targeting with specific groups can have the most potential for identifying eligible persons. What we would hope to do is identify some possible methods and test them and then, as a result of the tests, take those which appear to be the best methods and continue them in cooperation with interested groups.

We are planning on continuing the efforts of our district offices to communicate with advocacy groups, do public service announcements, and appoint coordinators in key offices as we have done for the homeless and in other areas where we see a need to communicate with those persons who are unable to reach us.

Acting Chairman DOWNEY. Do you do an assessment region by region of SSI eligibility?

Do you know, for instance, if some regional offices are doing a better job at outreach than others?

Mr. ENOFF. I would say a region may not be the best measure, but perhaps by the district office. It is difficult to measure.

As you know, statistically you can have a lot of applicants and not many eligibles. So I would say it is very difficult to measure the effect of outreach activities because although an office may be doing a lot, they may not be producing a lot of eligibles. That may be the result of a number of things.

What we have tried to do is publicize to other offices the best practices we have found. Sometimes you have to tailor-make those to a community because what worked in the heart of Manhattan may not work in rural areas.

Acting Chairman DOWNEY. One of the things that concerns me is that the Federal Government, in the past 8 years, has not pursued people who are eligible for benefits aggressively enough because of the budget crisis we face. Why aren't you saying, "look, you are eligible for the benefits and we want to give them to you."

I want to be sure in the strongest terms possible, and I think this is shared by Chairman Ford and other members of the subcommittee, we want to see the people who are eligible for SSI receiving these benefits.

We can confront the costs when they occur, but eligibility is clearly established. If you are eligible, you should get the benefits. We want to make sure if you are eligible, the Government does not stand in the way.

Mr. ENOFF. The problem has been reaching the persons who are eligible.

Acting Chairman DOWNEY. I look forward to your symposium, and I hope you can let us know about the ideas and solutions that come up.

You said you were studying disallowed claims. We would also like to know what your results are when that study is done.

Mr. ENOFF. We will be glad to share that with you. I believe our schedule shows that we would hope to have some findings in August.

Acting Chairman DOWNEY. You also mentioned a review of the list of childhood impairments.

Do you have a target for when that will be finished?

Mr. ENOFF. We have an ongoing review. I would say it has not been as current as I would like it to be. We should have, for instance, the childhood listings out this summer, that is, the childhood mental listings.

That covers a large portion of childhood cases. Right now our review is taking place in the cardiovascular area and the musculoskeletal listing will be well into the clearance process in September. That takes in more than half of the beneficiaries.

We need to establish an ongoing schedule so these reviews occur periodically. I hope we can do that.

Acting Chairman DOWNEY. Thank you.

Mr. Ford.

Mr. FORD. It was real interesting when you talked about disallowed claims. It might be that we are more concerned with how that message travels quickly and clearly to those who are eligible.

I am only making a comment. I know HHS has been committed, but I think the chairman has expressed it well.

Mr. ENOFF. That is a good point. We are criticized for not knowing what happens with the disallowed. The assumption is that those who are allowed were done correctly.

Mr. FORD. The message on the disallowed travels a lot quicker to the community than those who might be eligible as opposed to those applications that have been approved under SSI?

Mr. ENOFF. It may be the terminology, but I think that is why studying those disallowed has more positive potential.

Mr. FORD. I can agree with that. I join the chairman and look forward to your reporting back to us after your studies are released.

Acting Chairman DOWNEY. On the issue of presumptive eligibility, you say it is supportable to defer disability at birth on the basis of the genetic or congenital diseases.

Can you give us some examples of where this would be true for a child with spina bifida or Down's syndrome?

Mr. ENOFF. After talking with the medical staff, I understand that the way this disease expresses itself is different with different children. In spina bifida children, though, it may be detected at birth.

The concern we have is about presumptive disability based on future findings. Another concern would be once there is a finding of disability we have in the law the medical improvement standard to apply. What if the presumption is incorrect? We would rather

have evidence of a severe impairment at the time where the expression of impairment could be determined.

I recognize that also in some of the areas it is very difficult, as you may understand, to measure the mental capacity of a young infant. That is often true of an expression of Down's syndrome.

It is very difficult, and I don't pretend to say there is one answer. Each child can apparently express particular improvements in a different way even under some of the severe impairments.

Acting Chairman DOWNEY. Lastly, let me deal with the adequacy of SSI.

You say that an individual on SSI and food stamps would have a combined benefit equal to 80 or 90 percent of the poverty line and a couple would be 90 to 110 percent poverty. Only two out of five SSI recipients get food stamps. That leaves the other three out of five significantly below that level.

Are those figures correct? If they are not correct——

Mr. ENOFF. I cannot verify it. I will, for the record.

Acting Chairman DOWNEY. Would you?

Mr. ENOFF. Some SSI recipients have other sources of income. I don't know how that figures in. Let me see if we can identify the two out of five ratio and determine if it takes account of other sources of income.

[The following was subsequently received:]

It is not possible, given the data now available, to determine the exact number of SSI recipients who also receive food stamps. The rough estimate that 2 out of every 5 SSI recipients receive food stamps can be derived from Census Data.

However, this estimate does not take into account the fact that in California and Wisconsin SSI recipients cannot receive food stamps because the law allows these States to "cash out" the value of the food stamps by including a "food stamp bonus" amount in the State supplementary payments. Taking this into account, we can say that over 50 percent of all SSI recipients receive food stamps.

There are other reasons for nonparticipation of SSI recipients in the food stamp program, some of which are:

An indeterminable number of SSI recipients reside in households in which the total income is too high to permit the SSI recipients to be eligible for food stamps.

An estimated 5 percent (or 220,000 as of December 1988) of all SSI recipients reside in public institutions and are thus ineligible for food stamps.

Some individuals may wish to avoid the social stigma which is, to some, attached to the receipt of food stamps. While an SSI check is easily convertible to cash, food stamps have to be used in public and are easily recognizable.

Acting Chairman DOWNEY. We are anxious to increase the level of benefits. We will be in touch with you when the subcommittee goes through this process in markup. Unfortunately, it will not be very much because it is expensive to increase benefits for all recipients.

We are anxious to start the process of raising benefits to an adequate level.

Mr. ENOFF. I will be pleased to work with you.

Acting Chairman DOWNEY. Mr. Ford, do you have any other questions?

Mr. FORD. The staff has given me a question. The Maternal and Child Health Agency has funded a study about the problems of disabled children getting SSI and Medicaid. The report was prepared by the Harriet Fox Health Policy Consultants and completed last year.

Why has the Social Security Administration not released this report, and what does this report say?

Mr. ENOFF. That is not our report, but I would certainly be opposed to it being released. The methodology is flawed. I had a personal discussion with some folks from that association. What they did was to contact some of the Disability Determination Services and give a supposedly hypothetical description of a disability case and asked whether the person was disabled or not over the telephone. They asked that the Disability Determination Services staff make a conclusion based on the telephone conversation.

We asked that that be stopped. We put out information to all the Disability Determination Services. Apparently they did not stop, but went ahead. That study was funded by the Assistant Secretary for Health.

We wrote to him objecting to the study methodology, explaining that it was flawed and it was not the proper way to develop conclusions. If someone wanted to determine disability, they would have to have the evidence before them and not do it on the basis of a telephone conversation.

That is the reason we object to the study.

Mr. FORD. Then you have no plans of releasing the studies. Many of the criticisms we have heard about the SSI disability program for children is that we will not be privy to it if that report is not released.

Mr. ENOFF. I would certainly argue against that approach as the method for gathering reliable data. I would be glad to share with you what we find in our study or take other evidence which is informative. Where we have problems with those listings, we try to correct them. Gathering data over the telephone is not the way to do that. I don't know what is in the rest of the study. Frankly, I can't remember.

[The following was subsequently received:]

THE COMMISSIONER OF SOCIAL SECURITY
BALTIMORE, MARYLAND 21235

MAY 30 1989

COMMITTEE ON WAYS AND MEANS
RECEIVED
JUN 01 1989

The Honorable Dan Rostenkowski
Chairman, Committee on Ways and Means
House of Representatives
Washington, D.C. 20515

Dear Mr. Chairman:

One of our most important objectives at Social Security is to ensure that fair and equitable decisions are made on all of our beneficiaries' claims, including those claims filed on behalf of disabled children. We therefore share congressional concerns about recent allegations that Supplemental Security Income (SSI) benefits have not been awarded to a number of deserving children.

We are currently conducting a study of recently denied SSI childhood disability claims. The study includes objectives to determine whether the present criteria were properly applied and, more importantly, to determine whether the SSI childhood disability criteria accurately identify those children who should be found disabled.

We will be providing our analysis of the study's findings (targeted for completion August 31, 1989) for Secretary Sullivan's review. Additionally, Social Security Administration (SSA) staff members have met with the Ways and Means Committee staff to discuss this study. We will continue to keep the staff informed of the study's progress.

If the study shows that changes or additional training may be needed, I assure you that SSA will initiate appropriate remedial action.

I am sending a similar letter to Representative Archer.

Sincerely,

Dorcas R. Hardy

Dorcas R. Hardy
Commissioner
of Social Security

cc:
Representative Nancy Lee Johnson
Representative Robert T. Matsui

Acting Chairman DOWNEY. Thank you. The subcommittee is next going to hear from a series of panels. I want to apologize to the panelists. We ask you to summarize your statements in 5-minute blocks of time. If you would do that, I would appreciate it. If not, I will tap the gavel so we can get onto the next panelists. We will hear first from the panel, Community Legal Services, Jonathan Stein, general counsel, will be accompanied by Francesca Torres. The American Academy of Pediatrics, Dr. Avrum Katcher, who is a fellow at the academy. Protection and Advocacy, Inc., and Spina Bifida Association of Greater Los Angeles, Marilyn Holle, senior attorney, Protection and Advocacy, Inc.; Kaileigh Mulligan Foundation, Kathleen Mulligan, president; and the Association for Persons with Severe Handicaps, Suzanne Elrod, member, Committee on Social Security and Medicaid.

Mr. Stein.

STATEMENT OF JONATHAN M. STEIN, GENERAL COUNSEL, COMMUNITY LEGAL SERVICES, INC., ACCOMPANIED BY FRANCESCA TORRES, PHILADELPHIA, PA

Mr. STEIN. My name is Jonathan Stein, general counsel at Community Legal Services in Philadelphia. And we are lead counsel in a national class action now called *Sullivan* v. *Zebley*, in which the Third Circuit Court of Appeals found the eligibility criteria used by Social Security to be illegal under the act, too narrow, too arbitrary and not in conformance with what Congress intended when they passed the SSI provision to include disabled children in the early 1970's.

Essentially the heart of the decision is that poor disabled kids are not given an individualized assessment of all their functional limitations, and the reason for that is that this bureaucracy has been wedded to their listings of impairments, medical pigeonholes that have been unchanged for over a decade.

Despite what SSA Deputy Commissioner Enoff earlier said, there is no elasticity in the system, it is a very rigidly, narrowly imposed system which requires, I think, a real overhaul. We appreciate your bill, H.R. 868, which would take a major step in that direction.

Given the fact that the Government is fighting the *Zebley* decision, despite its commonsense approach that you look at all aspects of a child's disability, including the functional limitations of the impairments, and that they sought Supreme Court review of the case with the Supreme Court granting certiorari 2 weeks ago, we think it is particularly appropriate for Congress to clarify what its original intent was. Very briefly, these listings don't contemplate kids too young to be tested; they don't look at the combined effect of multiple impairments; they don't include many childhood affiliations like Tourette syndrome, which Ms. Torres will be speaking to as it affects her son; and they embody very high thresholds of severity, a point which Mr. Enoff didn't address to this committee.

For example, a muscular dystrophy kid must be in a wheelchair or braces to get SSI benefits. If he merely can't walk very well, and collapses at the end of the day, with a doctor advising against braces, that is insufficient to meet the high severity threshold of

the listings of impairments. This 5-year-old western Pennsylvania boy, Jason E., was denied SSI at age 5 despite evidence of his crawling on the school floor from exhaustion.

In my prepared testimony, we do suggest some fine tuning to H.R. 868: addressing this multiple impairments issue; clarifying the presumption of disability, which Ms. Holle will be addressing; instituting revisions of the child and mental listings.

Finally, we see, 5 years after the 1984 Reform Act, where Congress mandated that all the mental disorder listings, adult and children, be revised, SSA totally failing to revise the childhood mental disorder listings.

Social Security is getting around to announce once again that maybe this summer those listings will come out. We have good reason to believe those listings are insufficient, watered down by SSA after their own work group recommended changes back in 1986, 3 years ago. For this reason we suggest that Congress mandate the publication of that work group's listing revisions.

We also suggest that in reviewing all the childhood listings they don't do it as a one-shot effort, that they institutionalize reviews so we don't have to wait every 15 years to get a review of these listings.

Finally, we suggest that pediatricians be used in all the State agencies to evaluate child SSI claims. It is shocking to find out that pediatricians are not regularly used in reviewing kids' cases throughout the country.

I would like to hand the microphone over to a client of ours, Francesca Torres, whose son, Pedro, suffers from Tourette syndrome. Ms. Torres will explain what happened to her son this past 2½ years.

Ms. TORRES. Thank you. My name is Francesca Torres, as earlier mentioned, and I do have a son who turned 13 years. He was diagnosed with Tourette's Syndrome a couple years ago. He was about 6 or 7 years old when I first found out that he had a condition. When I first put Pedro in school, I knew something was not going right. I knew that something wasn't going right, and I went to the school principal and told them I felt something was not right.

So what the principal told me at that time is that I was comparing my children and that it wasn't fair to my child, and it was unfair to me as a parent. Because I had an older child and I had a younger child and he was not as—I didn't think he was as alert as the older one was and he was not up—as alert as the younger one was, this is why I guess the principal said that.

Anyway, after failing first grade, they finally started listening to me, he started listening, but that is as far as I got. Pedro started developing different motor movements. He blinks his eyes a lot—sometimes he blinks them so bad they swell and they turn blue over the eyelashes. He has been shunned by his peers. To this point, he says he has no friends.

I guess it is the hardest for me to deal with as a parent. Because he makes such loud noises because of his ticks, sometimes he sticks out his tongue, teachers have sent him to the office. I have been called to school because they say he is being a rude child, and he is not being a rude child. I tried to explain to them they have a condition, but they won't hear that.

After going through a lot of changes, I heard about SSI, or I knew about SSI and that certain handicapped people could get it. I was advised to try to get help for Pedro, which was my son. I went down to the Social Security Office on several occasions, and I tried to apply for Social Security, they said he didn't have a condition or at least one that met the criteria they were going by.

I would go back home, and I would get called back from home, I was constantly being called back from school, to the point where I lost my job because Pedro's condition got so bad I couldn't have him in school. I was called three to four times in a week, and I used up all my sick time, I used up all my vacation time, I didn't have any more time left.

At that point, I requested a leave of absence because of my son's condition. I was granted a leave of absence, but I couldn't find anyone to take care of him. It was an unpaid leave of absence. I couldn't find anyone to take care of him, and the one or two people who said they would—so I went back to Social Security and told them what was happening, but, again, I was turned down and was told my son did not meet the listings.

So then I came to Community Legal Services, and I met Jonathan Stein, and they told me that there was a way probably that I could get assistance if I talked, if I came out and said what my son's condition was and what the problems have been that I have been faced with. Pedro has been turned away by practically every kid in the neighborhood, even in churches he has problems. As parents, we love our child, and—I mean, parents can take a lot, but even at that point, when we first found out what was wrong with him, when he started making all these noises and facial expressions, we didn't know what to do about it, and we were harsh with him because no one said, "this is a condition, you can get help."

Through one of our doctors, we found out about the Tourette syndrome condition, and that is the first I heard about the condition and why he was doing all these weird noises and making all these facial expressions, to the point where here I am today.

I don't know how much good this is going to do or if it will do any good at all, but all I want to say is I am a working parent, and so is my husband. I am financially unstable, and I do have a lot of bills. Pedro's medication is very expensive, $70 a month, and because I have four other children, I have to consider that my job is not stable right now. If Pedro were to have SSI, not only Pedro but along with other children whose parents want to afford better housing and can't afford the medication, if Pedro were to have SSI, I could move out of my crack-infested neighborhood, which right now is doing big damage to him because he is insecure. He can't sleep in peace at that house, and there is no way I can see myself moving. I don't intend to use any of his moneys, if granted, for myself or my other children, but Pedro's insurance bills are very expensive, and I cannot afford it, that is another extra burden for me as a parent.

If nothing else comes out of this, please consider this is a real serious handicap for the family. I do community outreach work. I heard a couple here talk about outreach, and it is funny because I hear talk about AIDS prevention, I don't hear very much about Tourette or other syndromes. This is a serious condition, and I am

here to say it is a very serious condition. Only the persons that have been affected by it and their families know how serious. If it were known, I am pretty sure he will have a much easier time in school, he will have a much easier time on the playgrounds, and people will know this is a condition and life will be more bearable for him.

I meet a lot of young guys, good looking, and by talking to them, they look very smart, but they weren't given an opportunity to be in a special school or class where they could learn how to read and write and do things at their pace or level. Today when they are of age to collect trash, you need a high school diploma, these guys never made it through high school because it was so tough. If they would have had a special placement, they probably could have, but they weren't given that opportunity because of whatever their condition was.

So all I am saying is to consider all this, because it is important, maybe tomorrow, if my son is given the chance here today, when my son reaches 18, he will have a decent job and give back to society what he is getting now. If he is not given a chance, I don't know what he will do for a living tomorrow. I want it to be known that there is help if you people would turn around and really look at the serious problem these conditions can cause for children.

So I thank you for listening.

Acting Chairman DOWNEY. Thank you, Mrs. Torres.

[The statements of Jonathan Stein and Francesca Torres follow:]

TESTIMONY OF

JONATHAN M. STEIN, GENERAL COUNSEL

COMMUNITY LEGAL SERVICES, INC.

PHILADELPHIA, PENNSYLVANIA

Thank you Chairman Downey and Subcommittee Members for this invitation to testify. I am General Counsel at Community Legal Services in Philadelphia, where I have worked for the past 21 years providing civil legal aid services to low-income residents of our City. We have litigated the Zebley national class action which was brought on behalf of poor, severely disabled children who have been regularly, since the inception of the SSI program, denied SSI cash benefits and the Medical Assistance that accompanies the SSI award.

In August, 1988, the U.S. Court of Appeals for the Third Circuit held that the Social Security Administration regulation for determining children's disability benefits was inconsistent with the intent of Congress by excluding from the SSI program children with mental or physical impairments of "comparable severity" to those permitting awards to disabled adult claimants. Zebley v. Bowen, 855 F.2d 67 (3d Cir. 1988). The U.S. Supreme Court, at the government's request, has just this past May 15th granted certiorari to review this decision with a probable hearing in the late fall, 1989.

Before discussing the recent litigation in this area and your proposed legislation, a brief review of the disabled child plaintiffs in Zebley will show how arbitrary and deficient has been SSA's policy of evaluating children solely on the basis of whether they "meet or equal" the narrow, medical pigeonholes they call the child "Listings of Impairments."

Brian Zebley

Brian Zebley, brain damaged at birth in 1978, suffered from congenital brain damage with spastic right hemiparesis, mental retardation, developmental delay, eye problems and musculoskeletal impairments and paralysis on his right side. Although Brian was initially awarded SSI at age 2 upon a finding that he met the mental retardation listing, he was terminated less than two years later on the grounds that he "no longer met or equalled the requirements of any section of the Listings of Impairments at Appendix 1."

The Secretary found at an administrative hearing that "Brian Zebley has significant limitations compared with other children of his age," including very limited gross motor skills, spasticity and incoordination; misjudging of distances and frequent falling; and gross motion, self-help, and perceptual/fine motor skills were at or below 50% of a normal child. Yet, because the Secretary adhered literally and inflexibly to the numerical developmental delay requirements of one child medical disorder listing (mental retardation), and refused to make a broader, individualized assessment of

impact of the brain damage on the overall functional limitations of this four year old's life, Brian's benefits were terminated. 1/

Joseph Love, Jr.

Joseph Love, Jr. was 10 years old in 1983 when he was denied SSI benefits despite uncontradicted evidence of organic brain syndrome manifested by psychiatric and neurological impairments, including a severe adjustment disorder with mixed emotional and behavioral disturbances and hyperkinesis. 2/ Joseph failed first grade three times and could not even adapt to alternative special education classes, necessitating home-bound instruction.

At the time of the ALJ hearing, this 10 year old was functioning on a kindergarten academic level although he had been in school for four years. Educational failures had left him with "severe emotional stress."

Because Joseph could undertake some "self-care" activities (such as washing the dishes "occasionally"), he did not meet all

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1/ The mental retardation listing requires a delay in all developmental skills of no more than one half of the child's age. 20 C.F.R. Part 404, Subpart P, App. 1, § 112.05(A). At 48 months of age, although Brian showed some developmental delay in all skills, and delay in gross motor and self-help skills as great or more than one-half his age, Brian's development of non-motor skills, like cognition and language, put him in the 36-42 month range.

The Secretary finds that a listing is met "only when [an impairment] manifests the specific findings described in the set of medical criteria for that listed impairment. A finding that an impairment meets the listing will not be justified on the basis of a diagnosis [such as congenital brain damage or mental retardation] alone." SSA, POMS, DI 2109.B.

2/ Joseph also was diagnosed as suffering from an attention deficit disorder secondary to family stress and found "unable to relate with his peers, control his aggressions easily or learn." He went to sleep at 2:00 a.m., woke at 6:00 a.m., was unable to sit still, and constantly was climbing on top of things, sliding across the floor, running up and down steps, getting upset easily, and becoming depressed.

The Secretary has apparently deleted from his own Workgroup's proposed revision of the childhood Mental Disorder Listings, the section dealing with attention deficit disorders. This is why Section 2(c) of H.R. 868 should require publication of the 1986 experts' recommendations, and not give the Secretary further opportunity to promulgate clearly deficient revisions.

four of the "listed" criteria for childhood psychosis or non-psychotic disorders (see App. 1, Part B to 20 C.F.R. Pt. 404, Subpt. P, §§ 112.03, 112.04). 3/ Thus, since the individualized medical evaluation of functional impairment available to disabled adult claimants was precluded for Joseph, 4/ the Secretary denied benefits to an extremely maladjusted and emotionally disturbed ten year old who suffered from organic brain syndrome and a severe adjustment disorder.

A psychiatric consultant in the Secretary's national Office of Disability with twenty years of experience, Dr. Jerome Shapiro, admitted under oath at a deposition that Joseph Love, Jr.'s symptoms appear "often" in both children and adults, and while he acknowledged that an adult with such symptoms could be found disabled by an individualized assessment of residual functional capacity, a child with the "identical" symptomatology (who, like the adult, did not meet or equal the listings) would never be found disabled.

Evelyn Raushi

Evelyn Raushi was born mentally retarded in 1974, and was determined disabled upon meeting the listings beginning in 1979, but her benefits were subsequently terminated as of October, 1981 when the Secretary determined that her condition did not meet any listed impairment. Evelyn had an I.Q. of 64 and tests given by the Secretary's consultative psychologist also revealed "emotional immaturity and intellectual and social impoverishment consistent with [her] development delay"; "significant latent anxiety"; and, in addition

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3/ The relevant child mental disorder listings, "Psychosis of infancy and childhood" and "Functional nonpsychotic disorders," both require "marked restriction in the performance of daily age-appropriate activities; constriction of age-appropriate interests; deficiency of age-appropriate self-care skills; and impaired ability to relate to others . . . ." Part B, §§ 112.03 and 112.04 (emphasis added).

Despite Congress' 1984 Disability Reform Act, the Secretary and OMB have failed in revising and liberalizing these child mental disorder listings. Section 2(c) of H.R. 868 addresses this failing.

4/ The Secretary has issued a Social Security Ruling, SSR 85-16, to emphasize the "importance" and flexibility offered by an RFC assessment of an adult's mental disorder when the disorder does not meet or equal a listing. The Ruling, which specifically excludes "children under 18," requires a broad "overall assessment of the effects of the mental impairment" including evidence from social workers and family members in "assessing an individual's level of activities of daily living." SSR 85-16. See also 20 C.F.R. § 416.920a(c)(3).

to mental retardation, diagnoses of "developmental learning disorder", and "minimal brain dysfunction."

Although the Secretary found that Evelyn had suffered from mental retardation with an I.Q. in the 60-69 range, the evidence did not establish that she also suffered from a "significant impairment" other than the mental retardation. Thus, the Secretary concluded that the girl did not "meet or equal" the mental retardation listing, Section 112.05(C) of Part B of the listings. 5/ The Secretary's policies thus totally precluded the more flexible, individualized evaluation of this mentally retarded and emotionally disturbed girl's overall functioning. An adult would have received such consideration. 6/

Three separate Amicus briefs filed in the Court of Appeals on behalf of over two dozen disability and children's organizations nationally further established that Zebley class members include severely disabled children with such impairments as spina bifida, Tourette Syndrome, Down Syndrome, microcephaly and Prader-Willi Syndrome who have been "routinely rejected for SSI under the listings criteria." (Am. Br. of Pa. Protection & Advocacy, Inc. at 1-3, 20). An Amicus brief submitted by the Spina Bifida Association of Greater Los Angeles, et al., points out that many of the functional limitations of children suffering from spina bifida, such as gastrostomy tubes, tracheostomies and shunts from the brain, are not even recognized in the listings, resulting in such children being denied SSI. (Am. Br. at 2 as cited in 855 F.2d at 72-73.)

I am attaching a listing we have put together of representative past denials of SSI disability benefits nationwide to further document the Secretary's policies. Some children like some of these lucky enough to have skilled advocates but who have nevertheless had to wait years for an appeals tribunal to act favorably, do get awards, but far greater numbers never get denials reversed, or are deterred from even applying.

5/ This mental disorder listing requires that a child diagnosed as impaired by mental retardation with an IQ between 60 and 69 must also show a "physical or other mental impairment imposing additional and significant restriction of function or developmental progression." 20 C.F.R. Pt. 404, subpt. P, App. 1, § 112.05(C).

Again, the Secretary and OMB have five years after passage by Congress of the 1984 Disability Reform Act failed to revise and liberalize this child mental disorder listing to allow for fairness and more realistic evaluations of child mental disorders. Section 2(c) of H.R. 868 addresses this matter.

6/ See Social Security Ruling 85-16.

SSI Child Disability Law

Congress had provided in the Social Security Act's SSI Title XVI that adults will be evaluated for disability benefits based on their inability "to engage in any substantial gainful activity" measured by both medical and durational standards, and that a child will be deemed disabled "if he suffers from any medically determinable physical or mental impairment of comparable severity [to such adult]." 42 U.S.C. § 1382c(a)(3)(A) (emphasis added).

Children had not been eligible for benefits under the former federal-state program of welfare assistance for the disabled. (Title XIV of the Social Security Act, "Aid to the Disabled," 42 U.S.C. § 1351). In enacting the SSI program, Congress especially wanted to include poor disabled children because they were among the most needy and deserving of the minimum federal benefit level established by SSI. The House Ways & Means Committee Report, No. 92-231, supra, [1972] U.S. Code, Cong. & Ad. N. at 5133-34, observed:

> It is your committee's belief that disabled children who live in low-income households are certainly among the most disadvantaged of all Americans and that they are deserving of special assistance in order to help them become more self-supporting members of our society. Making it possible for disabled children to get benefits under this program, would be appropriate because their needs are often greater than those of non-disabled children. The bill, accordingly would include disabled children under the new program.

Congress also made clear that it wanted children to be found disabled if they had any impairments and limitations which would be found disabling in an adult, i.e. it intended to impose the same adult level of disability on children:

> A child under age 18 . . . would be considered disabled . . . if he suffers from any medically determinable physical or mental impairment of comparable severity (to one which would disable an adult).

H.R. Rep. No. 92-231, supra, [1972] U.S.C.C. & A.N. at 5134 (emphasis added). Such equal treatment furthered the basic goal to establish a uniform disability standard for all recipients in the new SSI program. Id. at 5233, and Cong. Mills' floor statement, 117 Cong. Rec. 21089 (1971).

The Secretary had earlier promulgated regulations setting forth a specific procedure for determining adult disability: an adult may meet specific medical requirements contained in "Listings" of impairments, may satisfy a medical equivalent of a listed impairment, or, if his or her disability does not fit into a listed

category, may further meet a separate residual functional capacities test, 20 C.F.R. § 416.920(e) & (f), sometimes referred to as an individualized determination. In contrast, the regulations promulgated in the mid-1970's prescribing the procedure for determining SSI children's disability provides for determination solely on the basis of Listings and medical equivalents to the Listings, and does not permit any type of individualized functional evaluation. 20 C.F.R. § 416.924.

Congress has nowhere provided that the "listings" test of § 416.924 constitute the sole test for children. It did authorize, in 1976, 4 years after the SSI program, the issuance of the Part B children's Listings criteria. Unemployment Compensation Amendments Act of 1976, Sec. 501(b), Pub. L. 94-566, 90 Stat. 2667. But Congress never stated at the time that these criteria were to be the sole test of eligibility, nor did it after publication of the Part B child Listings, 42 Fed. Reg. 14,707, 14,708-13 (March 13, 1977), ever approve this as the sole test. The Senate Finance Committee Report explaining the Sec. 501(b) mandate to publish children's criteria within 120 days criticized the "extraordinarily slow" development of guidelines for states and cited the need to insure program uniformity in the country. Sen. Report No. 94-165, 94th Cong., 2d Sess., reprinted in [1976] U.S. Code, Cong. & Ad. News at 6018-19.

The only relevant contemporaneous history to the above 1976 Act was Sen. Hathaway's statement that an assessment of "comparable severity" must include evaluation of the child's total ability to function within age-appropriate expectations. 122 Cong. Rec. 34025-26 (Sept. 30, 1976). 7/ The history cited by one court as

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7/ Senator Hathaway did not endorse Listings as the sole test for children's claims, and indeed there is no evidence that he nor others in Congress had before them the Listings to be used by the Secretary.

Senator Hathaway's remarks describe the children's "test of comparable severity" as one,

> [l]ike the test of determining the disability of an adult, [as] a disability is not determined solely on medical grounds, but also includes an evaluation of the impact of the disability on the person's abilities . . . The assessment [for children], rather [than focus on vocational ability] should refer to the impact of the child's handicap on his ability to function successfully within age-appropriate expectations. The child's functional capacity within the areas of learning, language, self-help

(Footnote cont.)

giving "tacit [sic] approval" to the Secretary's policy, was only a Senate staff committee report on the SSI program of April, 1977, 95th Cong. 1st Sess., p. 125 (Comm. Print), postdating the 1976 Act Amendments, which only then gave a general program description, noting the absence of non-medical vocational factors in the Part B criteria guidelines. See Powell by and through Powell v. Schweiker, 688 F.2d 1357, 1362 (11th Cir. 1982). The report, unattached to any pending legislation, does not affirmatively approve the listings policy or the refusal to provide children with a medical evaluation of all functional limitations, but rather explains only the absence of "non-medical vocational factors" (emphasis added).

Contrary to Senator Hathaway's expectations in 1976 of criteria that would be primarily determining functional impacts and criteria that would not be "restrictively drawn," 122 Cong. Rec. 34026 (1976), the Listings criteria ultimately published, and as blatantly acknowledged by the agency, "interpret[ed] severity in medical rather than functional terms." 42 Fed. Reg. 14705 (1977). There is no doubt that Congress has never explicitly approved these regulations as the sole test for the children's program.

Zebley Decision

Zebley is the leading case in the federal courts that has recognized that this regulatory framework clearly does not meet Congress' intent to provide benefits for children in a "comparable" way as adults. The court noted that the specific medical Listings, embodying high severity thresholds of disability, served only to identify the more extreme situations where functional disability could be presumed to exist, but were not exhaustive in identifying all potential severe mental and physical impairments:

> The listings however do not purport to be an exhaustive compilation of medical condition which could impair functioning to the extent necessary to satisfy the statutory standard

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(Footnote 7/ continued from previous page)

> skills, mobility and social skills are decidedly more meaningful in determining both the severity of the impairment and the developmental potential of the child.

122 Cong. Rec. 34026 (1976) (emphasis added). By limiting children to the Listings, the Secretary denies the practical and realistic evaluation of functional capacity as anticipated by Sen. Hathaway.

Similarly, Senator Bentsen's remarks show no intent to limit children to a Listings-only test, but only that a vocational factors test should be utilized. 122 Cong. Rec. 33301 (1976).

> for liability. The regulations recognize this by providing for individualized assessment of the actual degree of functional impairment of adults whose medical findings do not entitle them to a presumption of disability by meeting or equaling the listings. 20 C.F.R. § 416.920(e) and (f).
>
> As we explained above, the regulations do not provide for such individual assessment for children, although they are entitled by statute to receive benefits if suffering from "any" impairment of "comparable severity" to one which would render an adult unable to engage in "substantial" gainful activity. It is the expressed intention of Congress that children be given the opportunity to show that they suffer from "any" impairment of "comparable severity" to one which would actually, even if not presumptively, disable an adult.
>
> Therefore we find that the regulations are inconsistent with the statute in precluding a finding that a child is disabled unless his impairment meets or equals a listed one. 855 F.2d at 73-74.

Thus, by denying individual evaluations to children whose impairments do not meet specific medical listing requirements, the regulatory scheme treats children more restrictively than adults, a result Congress clearly did not intend when it stated that a child with any "comparable" impairment was entitled to benefits. An Illinois class action decision, with an excellent analysis and critique of the limitations of the Listings, comes to the same result. Marcus v. Bowen, 696 F. Supp. 364 (N.D. Ill. 1988).

In reaching its decision, the Zebley court distinguished the line of cases upholding the validity of the regulations as misreading the statute and relying on inconclusive legislative history. The court in Powell v. Schweiker, 668 F.2d 1357 (11th Cir. 1982), held that the regulations were adequate since some of the listings looked to functional elements in determining the medical criteria. However, as pointed out in Zebley, the fact that some of the listings incorporate a functional evaluation is inadequate; the statute requires that benefits be awarded for "any" disability of comparable severity.

> We reiterate that Congress has unambiguously expressed its intent that "any" impairment which meets the statutory standard shall be found disabling. The Secretary's regulatory method for determining disability, which is adequate to identify only some comparable impairments is not enough. 855 F.2d at 74.

In addition, the Powell court relied on a Senate Finance Committee Print published by Committee staff four years after the statute was passed as evidence that the Committee members agreed with the Secretary's regulatory scheme. The Committee Print, as noted above, is simply an after the fact summary of the reason vocational standards were not used for children and is not an indication of contemporaneous congressional intent at the time the original statute was passed. One of the three judges deciding the case in Powell dissented from the opinion, finding that "it is clear on its face that the Secretary has failed to provide a comparability standard as required by Congress." Powell at 1364.

In Hinckley v. Secretary of Health and Human Services, 742 F.2d 19 (1st Cir. 1984), the court focused on the inapplicability of vocational functional standards to children, again relying on language in the Senate Finance Committee Print. It is conceded that vocational standards were never intended by Congress nor sought by Zebley litigants to be imposed on the SSI children's program. The court in Hinckley further held that functional disability not specifically incorporated in the listings would be taken into account through medical "equivalence" to a listed impairment. However, as the Zebley and Marcus courts point out, the Social Security Administration explicitly prohibits consideration of functional ability in determining medical equivalence. See Social Security Ruling 83-19.

A number of additional cases in the federal district courts illustrate the arbitrariness of denials resulting from the rigidity of the medical listings. There are now class actions against the Secretary's child disability policies pending in Vermont, Tennessee, Wisconsin and Illinois. By focusing on SSA's elimination of the individualized functional evaluation available to adults but not to child applicants, courts like Zebley have correctly held that the Secretary of Health and Human Services has clearly exceeded his authority by promulgating regulations directly conflicting with Congressional intent.

Given that the Social Security Administration has been so rigid and adament in adhering to its eligibility policies despite their devastating effect on poor, disabled kids' access to SSI and Medicaid, it is entirely appropriate for Congress now to clarify and reiterate the original intent of the law through legislation like H.R. 868. In doing so, the Congress will be concurring in the pursuasive reasoning of the Zebley and Marcus courts that SSA has long been misconstruing the SSI children's disability law.

Fine Tuning of H.R. 868

H.R. 868 is an outstanding initiative that this Subcommittee has undertaken, but a number of further revisions may be warranted to fully address the pervasive problems of unfair claim denials.

Multiple Impairments

Section 2(a) could be improved by explicitly addressing the fact that currently SSA never evaluates the combined effect of multiple childhood impairments. This is due in large part to the fact that evaluations tied to "meeting or equaling" particular narrow Listings of impairments offer no methodological vehicle for taking a look at the whole child. Despite a prior mandate in Section 4(b) of the 1984 Social Security Disability Reform Act, P.L. 98-460, to evaluate the "combined effect of all of the impairments" in adult and child claims, this is most often not done for children. We suggest, then, the insertion in Section 2(a), p. 2, at line 13: "limitations, and the combined effect of multiple impairments." This then would become a key part of the individualized assessment that Section would require.

Presumption of Disability

To clarify this vitally important section as one intended for children who are too young to manifest the laboratory and clinical signs and symptoms required by the Listings, but who are known to have a disabling genetic or other impairment, we suggest inserting at p. 2, line 20 "or other impairment" in the heading, and on p. 3, at lines 1-9, substitute the following which retains most of the original subsection:

> However, any child under the age of 4 years with a genetic or other diagnosed impairment shall be presumed to be disabled or blind for purposes of this part if applicable clinical and laboratory techniques cannot be administered due to the child's age, and it is probable that such techniques would demonstrate that the child suffers from a medically determinable physical or mental impairment that would render the child eligible for benefits under this title by reason of disability or blindness.

Childhood Mental Impairment Listings

The Secretary has for five years now failed to carry out his duty under Section 5(a) of the 1984 Social Security Disability Reform Act, P.L. 98-460, to "revise" under contemporary medical findings and make more "realistic" the "Mental Disorder" Listings, which include Part B, the childhood mental impairment Listings. The Secretary did these revisions for adult claimants but failed to adopt his own Workgroup's recommendations for children submitted to the Associate Commissioner for SSA on April 1, 1968. We do know that the outstanding Workgroup's revisions were altered in the agency by deleting at least the addictive disorder and attention deficit disorder listings criteria. Thereafter, OMB killed the entire revision.

Given this total abdication of responsibility and reckless disregard for the lives and well-being of mentally impaired children, we believe that Section 2(c) of H.R. 868 should give no further time to the agency to promulgate what mental health professionals agree were deficient mental impairment listings revisions. We suggest that Sectopm 2(c) require HHS within 30 days of enactment to publish in final form the Workgroup's recommendations of April 1, 1986, and to require SSA to make them applicable to all denied mental cases since the effective date of the 1984 Reform Act's mandate to revision (120 days after October 9,1984).

Review Of All Childhood Listings

Section 2(d) embodies the excellent requirement of reviewing and revising all the listings. This would be the first such review in over 13 years.

But to learn from the experience of an agency that has all but neglected its obligation to update the Listings, we suggest that Congress amend Section 2(d) to institutionalize such reviews and revisions so that this is a continuous process, or at least that such reviews be undertaken every two years.

We also suggest at p. 4, line 1, that you add "representatives of child disability advocacy organizations," to those participating in these reviews and revisions to insure enlightened, outside input for an agency that has too frequently shunned assistance from those representing its clients.

Use Of Pediatricians

The state disability determinations agencies under contract with the Secretary and SSA to do the disability evaluations of claims, make virtually no use of pediatricians or their own medical staff. These staff physicians work closely with claims adjudicators to assess impairments. The agencies also make limited use of pediatricians and pediatric specialists when consultative examinations are purchased to supplement inadequate existing medical reports.

Requiring the use of pediatricians in the state agencies and for all consults will lead to more expert and fair evaluation of children's SSI claims. The experience in Massachusetts, where the state agency took this initiative by centralizing children's claims to allow for expert, pediatric evaluation, has proved that the quality and fairness of decision-making has greatly improved. It is time that this common sense and priority reform be included in a new section of H.R. 868 to give disabled kids a fair shake in the disability evaluation process.

Ongoing Litigation

The ongoing Zebley litigation, now before the U.S. Supreme Court, shows that despite the Third Circuit's view of the current SSI law, as requiring individualized assessments of functional limitations, the Social Security Administration's refusal to abide by that decision calls for Congress to clarify and reaffirm its view of what the SSI law has called for all along. We think that it is appropriate in these circumstances for the Congress to state its agreement with the Zebley holding and, by legislating a clarification in the law, stating that it is not precluding the federal courts from affording whatever relief they deem just and appropriate for plaintiffs and class members before them in Zebley and any other pending similar actions pending in Vermont, Tennessee and Wisconsin.

Thank you for this invitation to appear today as well as your conscientious concern for the well-being of our most vulnerable children.

SUMMARIES OF SOCIAL SECURITY ADMINISTRATION DECISIONS DENYING SSI BENEFITS TO CHILD CLAIMANTS

Pennsylvania cases:

Dean Q. -- spina bifida, Epstein-Barr virus, chronic diarrhea

Dean was denied benefits by an ALJ when he was two years old. He suffers from breathing problems, spina bifida, conjunctivitis, learning problems, anemia, and hyperactivity. His mother reports that he is destructive and occasionally bites himself. He has been hospitalized several times for dehydration with vomiting and diarrhea. He has been diagnosed as having Epstein-Barr virus; his chronic diarrhea (as diagnosed at Johns Hopkins Hospital) is listed as a symptom.

Weekly developmental therapy was prescribed when Dean was evaluated at age 26 months as having gross motor skills of 19 months, fine motor skills of 18 months, and cognitive and language skills of 17 months. He is in the 25th percentile for weight for his age and the 10th percentile for length, as noted by the ALJ. WIC has placed Dean in the high nutritional risk category. In his most recently listed evaluation, he was listed as having a 7 month delay in cognitive skills and an expressive language delay of 15 months, making him "significantly delayed."

Despite these impairments, the ALJ rejected Dean's attorney's argument that Dean's functional nonpsychotic disorder met listing 112.04 of the children's disability regulations (mental and emotional disorders). The ALJ stated that "while the child does have some physical problems and some slowness in mental and motor delay, he does not have an impairment or combination of impairments either listed in or medically equal to one listed . . . ."

Henry R. -- mental retardation, developmental disability

Henry was denied benefits by an ALJ when he was ten years old. In his Social Security consultative psychological exam, Henry tested as having a verbal IQ of 49, a performance IQ of 68, and a full scale IQ of 54. Although these scores alone satisfy child listing 112.05(B), the ALJ discounted the scores because the administering doctor diagnosed Henry as "only" mildly retarded. However, even in addition to these scores, Henry tests three years below his chronological age on Developmental Test of Visual-Motor Integration and two years below in Visual Aural Digit Span Test. These results indicate perceptual dysfunction that should itself constitute organic mental disorder under listing 112.05(c). Henry is maintained on Ritalin because of his hyperactivity, lack of concentration, and behavioral problems. Although he must continue to undergo behavior therapy, the ALJ determined that he did not specifically meet a listing and was therefore not disabled.

Richard D. -- chronic asthma, respiratory tract infections

Richard was denied benefits by an ALJ when he was six years old, and the denial was upheld by the Appeals Council. Henry's asthma required 17 emergency room visits and six periods of hospitalization during the approximately two year period from November 1984 to January 1987. He missed 67 days during his 8 month pre-school program and 21 out of 103 days of kindergarten. He uses a breathing machine 4 times a day for at least one hour at a time, and is presently taking Slobid, Alupent, and Prednisone. Henry is also plagued by complications by respiratory tract infections. Despite these clear functional impairments, the ALJ determined that Richard's condition did not meet the recent, recurrent, and intense requirements for the bronchial asthma listing (103.03).

Jason E. -- muscular dystrophy

Jason was denied benefits by an ALJ when he was five years old. His denial was eventually overturned four years later by a federal district court in 1988. According to his attorney, if Jason had been awarded benefits earlier, "his condition perhaps would not have deteriorated as rapidly." For example, occupational therapy had been recommended three times per week, but Jason's family could not afford the treatment.

At the time of denial, Jason had difficulty walking and was unable to grasp and control a pencil. He needed help dressing and eating and required speech therapy since his mouth and vocal cords were affected by his degenerative disease. He often crawled at school because he became exhausted by the end of the day. Despite the medical advisor's testimony that muscular dystrophy "results in motor dysfunction grossly affecting both his upper and lower extremities, which definitely interferes with age-appropriate daily activities," Jason was initially denied benefits because he did not meet listing 111.06 for motor dysfunction. He has now experienced hypertrophy of calf muscles and "disruption of fine and gross movements and gait and station," and is confined to a wheelchair or carried by his parents.

Yolanda D. -- mental retardation, developmental disability

Yolanda was denied benefits when she was 11 years old. Her latest IQ test revealed a verbal IQ of 72, performance IQ of 84, and full scale IQ of 76. She is enrolled in a special education/educable mentally retarded class, and, according to her teacher, requires more personal attention and has lower achievement than any other student in the class. Yolanda's personal hygiene is well below average, and she "wets and soils her clothes at home and at school." Both her visual motor integration and language development and communications skills are extremely delayed. Although the ALJ acknowledged that "because of her mental ability,

she would be limited to simple, repetitive tasks," he found that she did not meet listing 112.05 for mental impairments.

Harvey M. -- Gran mal epilepsy

Harvey was denied benefits by an ALJ when he was eight years old. He suffers from gran mal epilepsy with a history of psychomotor seizures, during which he either experiences generalized shaking or sits and stares. Harvey also has a history of conduct disorder and his "fine motor control and the auditory and visual memory retention [are] poor and he needs special assistance to acquire the necessary skills to function." An IQ test administered in June, 1987 revealed a verbal IQ of 70, performance IQ of 91, and full scale IQ of 79. The evaluation also showed "limited abstract thinking," and "[h]is coordination dexterity and manipulation skills were below a first grade" level. The ALJ held that Harvey's condition did not meet listing 111.02 because his condition could be treated.

Joseph L. -- organic brain syndrome

Joseph was denied benefits at age ten. He suffers from organic brain syndrome manifested by psychiatric and neurological impairments, the most pronounced of which are an adjustment disorder with mixed emotional and behavioral disturbances and hyperkinesis. In his early childhood, Joseph would go to sleep at 2 a.m., awaken at 6 a.m., constantly climb onto things, and run up and down steps. He failed first grade three times, could not adapt to special education classes, and required home-bound instructions. He was only awarded benefits by being a plaintiff in the Zebley litigation in the U.S. District Court in Philadelphia, Pennsylvania.

Northeastern cases:

Valerie H. -- cystic fibrosis, diabetes, asthma, scoliosis
Vermont

Valerie was denied benefits when she was sixteen years old. She has had cystic fibrosis since birth and is hospitalized for a week every two or three months for pneumonia resulting from her disease. In 1986, her treating physician reported that her cystic fibrosis would lead to a shortened life expectancy. Valerie also suffers from diabetes, asthma controlled by medication, and scoliosis. She takes forty pills per day plus insulin and use of an inhaler. She has asthma attacks approximately once a week.

The ALJ found that Valerie did not meet the specific requirements for the listings for cystic fibrosis, asthma, diabetes, or scoliosis, and refused to consider her impairments in combination. Despite a doctor's opinion that Valerie was disabled, the judge noted that "[i]n the absence of pulmonary function test

results which meet the specific criteria of the section dealing with cystic fibrosis (section 103.03), no finding of disability can be made."

M.B. -- severe personality disorder
Vermont

M.B. was initially denied benefits as a child, but at a rehearing at age 22 was awarded benefits as an adult based on the same medical evidence but applying the adult test. M.B. was diagnosed as a child with "adjustment disorder with mixed disturbance of emotions and conduct and a mixed developmental disorder." She was removed from her natural parents at age two because of physical abuse. She was then removed from adoptive parents and a subsequent foster home for suspected sexual abuse, and was moved approximately 20 times through successive foster home placements. A child psychiatric social worker who, conducted regular therapy determined that M. "had not developed a level of emotional maturity sufficient to function without support."

M. has attempted suicide at least three times (at least once requiring hospitalization), has threatened teachers with physical violence, and was arrested and held in prison for assaulting a police officer. Her emotional disorder causes her to become angry and frustrated very quickly, and she is unable to control her mood. Her school administrator stated that her "emotional instability kept her from doing functional school work."

Despite the ALJ's finding that "the claimant has a medically determinable mental impairment," he found she could be considered disabled only under the residual functional capacity test available only to adult claimants, and not under the specific listing for mental impairment applicable to children under age 18. He acknowledged that her condition was essentially the same before and after age 18, but awarded benefits only as of the date of her eighteenth birthday. After being denied on multiple levels of rehearing, M.B. was finally awarded benefits by the Appeals Council retroactive to the date of her initial application.

W.B. -- seizures, mental retardation
Vermont

W. was diagnosed at age two with severe behavior and seizure disorder. He has been hospitalized repeatedly, for example six times during 1982 for seizures, Dilantin toxicity, gastroenteritis, vomiting, and dehydration. W. has been hospitalized several times for uncontrolled seizures, and a doctor testified that they are still not controlled.

Intelligence tests administered in 1982 revealed a verbal IQ of 52 and a performance IQ of 60. In 1981, a psychiatrist's evaluation was that W. was an "extremely handicapped individual who needed continuing support and further psychiatric treatment . . . [who was] totally dependent on his parents, suffered from epilepsy and had a mild degree of mental retardation and behavioral problems

in the form of expletive outbursts." His father testified that W.B. functioned as a five or six year old child.

W. originally applied for benefits in 1980, and after repeated denials and rehearings, was finally awarded benefits in 1986. The award appears to be based solely on the results of the 1982 IQ test, under listing 112.05(B) (IQ of 59 or less), rather than on the combination of medical and functional impairments that also existed before that date.

Midwest and Southwest cases:

Blake D. -- asthma, gross obesity, hypertension
Texas

Blake was denied benefits when he was eleven years old. At that time he weighed 241 pounds, was 64 1/2 inches tall, and had recorded blood pressure of 130/110 (which had reached a high of 190/110). Blake has been hospitalized several times for asthma and has been diagnosed with hypertensive encapalopathy, vertigo, severe headaches, asthmatic bronchitis, and an endocrine disorder. He has difficulty breathing and has daily nosebleeds; he was once hospitalized for a weeklong nosebleed. He is too young to be prescribed medication for his hypertension. Blake has had headaches so severe as to cause temporary loss of vision.

The ALJ found that Blake did not meet the listing requirement for either asthma, obesity, or hypertension. The listing for children's obesity did not contemplate a child's weighing as much as Blake did at the time of decision, and the ALJ refused to evaluate Blake by adjusting the adult weight listing to account for the expected continued weight gain of children. Blake has filed an appeal for benefits in federal district court.

Jennifer C. -- anorectal atresia, bladder dysfunction
Iowa

Jennifer was denied benefits at age five. As an infant, Jennifer underwent surgery performing a colostomy, relocation of anus, and then closing of the colostomy. She now suffers from chronic constipation that will require additional surgery. She is unable to sense when her bladder is full and constantly wets herself both at home and during school. Her bladder dysfunction is accompanied by repeated urinary tract infections. A doctor testified that Jennifer's "constant constipation affected her personality significantly." In addition, Jennifer has an eye muscle deficiency resulting in a lack of peripheral vision diagnosed as Duane's Syndrome.

The ALJ held that no single one of Jennifer's disabilities met a required listing. The judge specifically rejected an evaluation of "functional impairment from her multiple disabilities" on the grounds that such an evaluation constituted a residual functional capacity determination not permitted under the child disability

regulations.

Takesha -- spina bifida, paralysis, club foot, hip disorder
Illinois

Takesha was denied benefits initially and on reconsideration. She is now eight months old. Takesha suffers from spina bifida, characterized by a sac formed around her fifth vertebrae that has caused damage to her nerve roots. As a result, she is permanently paralyzed from the knees down and will require braces or some assistance. She also suffers from non-compensated hydrocephalus, where the accumulation of fluid in her brain cannot be corrected by use of a shunt. Takesha was hospitalized for most of the month of January. In addition, she has a club foot a hip disorder resulting from her other medical impairments.

In February, 1989, an ALJ reversed the earlier administrative decisions and awarded benefits to Takesha based on her impairment as medically equivalent to child disability listing 111.08 for spina bifida.

Southern cases:

Kendrick B. -- cystic fibrosis
Mississippi

At the age of three months, Kendrick was diagnosed with severe anemia, growth retardation, and pancreatic cystic fibrosis. Although he received SSI benefits for two years, the benefits were discontinued when an ALJ found that he did not meet the forced expiratory volume test required by the pulmonary disorder listing. Despite Kendrick's mother's claim that she could "not afford to continue purchasing the medication" necessary to maintain his condition, the Fifth Circuit Court of Appeals affirmed the denial of benefits for failure to meet the listings. Burnside v. Bowen, 845 F.2d 587 (5th Cir. 1988).

Brittany D. -- partial trisomy 3 p chromosome
Tennessee

Brittany was initially denied benefits when she was less than one year old, and the denial was upheld by an ALJ when she was approximately 19 months old. At eight months old, she was diagnosed as mentally retarded with a developmental age equivalent of 5 1/2 months. In the same evaluation, the examining medical consultant diagnosed "chromosomal aberration associated with craniofacial dymorphism, congenital heart defects and mental retardation." Brittany suffers from a large umbilical hernia, repeated seizures and fevers, and recurrent pneumonia. Her developmental age equivalents under the Bayley Scales of Infant Development were all delayed more than one half of her chronological age.

Despite Brittany's tested severe developmental delay, the Secretary found that she did not meet listing 112.05(B) for mental retardation. The listing recognizes only standardized IQ testing and does not consider infants that may be too young to be tested.

Stephanie M. -- brain damage, apnea, immunodeficiency problem
Tennessee

Stephanie was born prematurely in April, 1988. She suffers from a seizure disorder, immune deficiencies, and had an abnormal EEG in August. Stephanie cannot sit up, control her head, or roll over. Stephanie was denied benefits both on initial application and rehearing, although no specific listing was noted as not being met. As suggested by her attorney, she is a good example of a child with multiple disorders, none of which meets one specific child disability listing but which cannot be considered on their combined effect.

Christina -- cerebral palsy, severe developmental delay
Tennessee

Christina is now almost two years old. She has been denied benefits both on initial determination and on reconsideration. She has been diagnosed with cerebral palsy and suffers from hydrocephalus ("water on the brain") requiring two shunts to drain fluid. Christina is not able to sit up, crawl, or walk without assistance and is severely developmentally delayed. In addition, she has strabismus (crossed eyes) for which she will require surgery. Despite her impairments, the Social Security Administration has determined that she does not meet the listings for cerebral palsy.

R.S. -- fused spine, developmental delay
Tennessee

R.S. is two years old and has been denied benefits both by the Social Security Administration and on appeal to an ALJ. His cervical spine is completely fused. As a result, R.S. has no motion in his neck and severely limited use of his arms. According to his attorney, he is at constant risk that a wrong movement could snap a piece of his spine. In addition, R.S. is developmentally delayed and resides in an in-home psychological program.

The ALJ found that R.S.'s impairment did not meet the musculoskeletal listing and did not consider his developmental delay.

James Derik -- chronic liver disease, allergy to all food
Alabama

James Derik was a 10 month old child with Alpha I Antitrypsin deficiency, a rare chronic liver disease. Derik is essentially confined to his home, leaving only for doctor visits. He has been hospitalized four times since birth. Uncontroverted medical

evidence established that his condition is life long, precluding a normal childhood and adult life. He arms, legs and feet swell up causing pain. He has allergic reactions to any kind of food, and he has a limited ability to eat. He runs a fever three or four nights a week. Derik requires constant attention and when he experiences swelling, must be held all night. In addition to his liver disease, Derik has a history of associated mild conjunctivitis and hepatomegaly, left inguinal hernia, gastroenteritis, and developmental delay.

Derik's application for SSI was denied five times, including at the federal district and circuit court levels, on the grounds that his condition did not meet the listings. Wilkinson v. Bowen, No. 86-7855 (11th Cir. July 15, 1987).

West Coast cases:

Russell C. -- lead poisoning

Russell was a ten year old boy who suffers from the residual effects of being lead burdened as a young child. The damage from being lead burdened manifests itself in various ways: in poor auditory memory and sequencing, in significant delays and deficits in fine and gross motor areas, and in visual-perceptual motor integration at the level one would expect of a child at age 5 1/2 to 6 years. He scored low on tests measuring his level of social adaptiveness, he has behavioral problems, and he cannot write his last name.

Tiffany M. -- Down's syndrome, congestive heart failure

Tiffany was a three year old girl with congestive heart failure in addition to Down's syndrome. At the age of 15 months, Tiffany was found to have a developmental delay of over fifty percent. The symptoms of her severe heart and pulmonary conditions include difficulty breathing, decreased physical ability, repeated pneumonia and decreased ability to withstand infection. She has required extensive medical treatment for her problems. According to her doctors, her growth early in life could have been promoted only by the "expertise" and "tenacity" of her foster mother.

Despite her severe medical impairments, Tiffany was denied SSI benefits initially and upon reconsideration. Her claim was finally granted over one year after her application was filed. The notice of reconsideration dated April 15, 1985 (over 14 months after Tiffany was born) states that although Tiffany has Down's syndrome,

> It is impossible to fully assess any limitation this condition might have on her mental capability due to her young age. Therefore, the severity of your child's condition does not meet the severity of the special requirements for Disabled Child's benefits.

Angela L. -- respiratory distress syndrome, profound central nervous deficit

Angela L. was a 10 month old girl who suffers from respiratory distress syndrome and a very profound central nervous deficit. Due to these impairments, Angela has the developmental status of a newborn infant. She has no functional use of any extremity and must be fed by a gastrostomy (feeding) tube. She also requires constant supervision to ensure that she keeps breathing. She needs percussion and pulmonary hygiene on a routine daily basis to clear secretions from her lungs.

Angela's twin sister, Amy was granted SSI benefits upon her initial application. A comparison of the medical records of Amy with those of Angela demonstrate that the infants had very similar functional limitations, but that there were some minor differences in their test results. Apparently, Amy's test results did meet a listing, while Angela's did not. According to their social worker, both twins have a similar degree of respiratory distress.

Courtney M. -- Down's syndrome, choanal stenosis

Courtney was a 16 month old girl with Down's syndrome. She also suffers from choanal stenosis, a chronic blockage and scarring of the nasal passages due to chemical burns which were caused by a mistake in her treatment at the hospital. She has had multiple health problems requiring frequent hospitalizations since her birth. She receives most of her nourishment through a feeding tube, and she requires close supervision by a trained person to monitor her feeding and to keep her nasal passage open. Courtney now sees a total of six physicians to monitor and treat her multiple health needs. According to Courtney's social worker, the family's finances are strained due to extensive medical treatment, and Courtney's health problems have caused and continue to cause great anxiety.

Despite her severe disabilities, Courtney twice has been found not to be disabled: once upon her initial application for SSI and once upon appeal. The initial and reconsideration decisions both reflect that extensive evidence of Courtney's condition was provided to the Social Security Administration, and that Courtney nonetheless was found not to meet the "special requirements for SSI benefits for a disabled child."

Katrina P. -- cystic hygroma, hemangioma

Katrina was 12 1/2 months old. When her SSI application was filed, she had already had a tracheostomy (an opening in the neck for breathing and through which mucous must be regularly suctioned) and a gastrostomy (tube into stomach for food and liquids). The hygroma/hemangioma is a large tumor which obstructs breathing and eating passages. It is expected to continue growing for several years.

Katrina's mother is unable to continue working because of

Katrina's need for constant skilled supervision. Due to lack of funds, Katrina and her mother live in a cockroach infested apartment. Nurses have observed cockroaches crawling into Katrina's suctioning equipment. Katrina's mother is very depressed and suffers from lack of sleep because she must constantly listen to be sure Katrina is still breathing.

Yukiea B. -- hydrocephalus, myelomeningocele (spina bifida)

Yukiea was a six month old child with a congenital birth defect consisting of hydrocephalus and myelomeningocele (an incompletely fused spine) or spina bifida. A surgical tube has been placed in her head to drain off excess water as it collects on the brain. She is unable to crawl or use both legs due to partial leg paralysis. Her partial paralysis and loss of bladder and bowel control are expected to be permanent. She will require intensive and ongoing medical care for the rest of her life, according to her doctors. Yukiea's mother was forced to quit working to take care of her.

Jeffrey -- Tourette's Syndrome

Jeffrey was a thirteen year old with Tourette's Syndrome, a severe neurological disorder. Jeffrey's syndrome causes persistent disorganization of motor functions, including all four extremities, on a regular basis. Jeffrey also suffers from severe and frequent facial tics, nervous jerks, and uncontrollable grunts and barking caused by his condition. Jeffrey's ability to participate in normal activities is severely restricted. He has extreme difficulty concentrating and engaging in normal play activity.

February 25, 1989

TESTIMONY OF

FRANCESCA TORRES,

MOTHER OF PEDRO ORTIZ,

PHILADELPHIA, PENNSYLVANIA

Thank you, Chairman Downey and Members of the Subcommittee for this invitation. I am Francesca Torres, a working mother of five beautiful children. One of my children, Pedro, age 13, has been diagnosed with Tourette Syndrome since age seven (7).

Tourette Syndrome is believed to be a hereditary neuro-psychiatric disorder that is manifested by multiple facial tics, eye blinking, vocal noises and sounds, which can't be easily controlled. When Pedro failed first grade and had observable delays in his development, along with the twitching and vocal shouts of Tourette Syndrome, I knew then that he would require special care and attention. Tourette Syndrome has caused Pedro much physical and psychological pain. His eye blinking can be so continuous that his eyes swell in pain and become blue over his eyelashes. Because he is so different from his peers and siblings - although like any other child, he tries to conform and cover up his medical problems - he is shunned by others and says, even today, that he has no friends.

A year ago, while attending Sheridan Public School of the Philadelphia public school system, an insensitive teacher put Pedro in a supply closet in order to separate him and his vocalizations from the rest of the class. Because of Pedro's difficulties in coping with his condition, he has developed what a psychologist has called an "Adjustment Disorder" to describe the emotional problems he has developed over time.

I had to resign my employment position at Catholic Social Services to be able to be at home with Pedro because he had total sleepless nights for two (2) to three (3) days at a time and there were days when his medical condition resulted in his behavior being considered a disruption to school officials, who would send Pedro home on many occasions.

I wasn't aware that SSI was available for disabled children until 1986, when I applied for SSI for Pedro. The Social Security Administration (SSA) keeps the knowledge of this benefit a virtual secret from parents of disabled children. Although the state disability agency recognized that Pedro had Tourette Syndrome, they denied the claim because he did not meet or equal the SSA's "Listing of Impairments." A reconsideration appeal was also denied despite the fact that throughout the entire application process Social Security had three (3) treating doctors' reports, a school report and consultative examination reports from a neuro-psychiatrist and a clinical psychologist.

During this time I had to go on AFDC welfare for a period of almost two (2) years. I was determined to get back into employment, obtain my General Equivalence Diploma and join the Philadelphia Health Management Corporation (PHMC) as a community health outreach worker on AIDS prevention. Because I lost my medical assistance while I was unemployed, I had no money to

spend the $75.00 a month on Pedro's Haldol and Artane medications; Pedro regressed, losing control more often, not sleeping and becoming very accident prone. For example, recently, while at school during a gym class he lost control of his balance, grabbed the volleyball net to control his balance, which resulted in a net pole falling on his head, cutting his upper left eye and requiring three (3) days of hospitalization. Because I had only been working less than thirty (30) days at PHMC, I initially had no health insurance coverage. I now owe St. Christopher Hospital for Children in Philadelphia, Pennsylvania almost $6,000.00 to cover the hospital bills that resulted from this accident.

Although Tourette Syndrome has been known for over one hundred and sixty (160) years, it seems to be new to the SSA on their "Listing of Impairments," which is the sole eligibility criteria for SSI children's disability that does not even recognize this disorder. Your bill, Representative Downey, would help children like Pedro by requiring the government to do what they should have been doing throughout history of this program: to consider the functional limitations that a childhood disorder like Tourette Syndrome places on a child's school performance, motor coordination functioning, relationship with siblings and peers, perceptual problems, impaired reality testing and the financial, emotional and social stress that is placed upon the child's family environment. In sum, taking a

fair, realistic and whole view of the child and the child's problems associated with this disease. Your bill would also require SSI to review all its childhood listings, something that the SSA should be required to do on a regular basis.

If Pedro is granted SSI benefits, I could better provide for his needs. I could move out of our crack-infested neighborhood, where we have been repeatedly burglarized with Pedro living in constant fear, thus, making him more vulnerable because of his emotional problems which exacerbate his motor coordination problems. I would also like Pedro to attend a private school for children with impairments like Tourette Syndrome, since he has not made adequate progress in the learning diabled public education classes he has been attending.

Last week, on May 25th, two and a half (2.5) years after our SSI denial, we had our first, in person, hearing before an Administrative Law Judge on the appeal of Pedro's claim. Whatever the outcome, I hope you will work hard to see that Congress passes this legislation on behalf, not only of Pedro, but of thousands of other disabled children. Thank you.

Acting Chairman DOWNEY. Dr. Katcher.

STATEMENT OF AVRUM L. KATCHER, M.D., FELLOW, AMERICAN ACADEMY OF PEDIATRICS

Dr. KATCHER. Mr. Chairman, I think I could only add that I am happy to be here with Mrs. Torres.

Mr. Chairman, my name is Avrum Katcher, M.D. I am a practicing pediatrician from Flemington, N.J. I am a fellow of the American Academy of Pediatrics, and a member of the academy's committee on children with disabilities.

Our academy represents over 38,000 pediatricians in the United States who care and advocate for the well-being of children, infants and adolescents. We strongly support H.R. 868, the SSI Disabled and Blind Children Act, which you and Mr. Matsui have introduced. We commend you for your leadership. If enacted, we think this legislation will correct many inequities in the children's portion of the supplemental Social Security income program.

We feel the childhood listings are medically inappropriate, the comparable severity standard for determining disability does not allow a functional assessment and is more restrictive for children than adults, and children with certain genetic or congenital impairments which lead to disability are excluded from the program.

I would like to address each of these issues. First, the presumption of disability: SSI refuses to make a finding of disability in young children with congenital impairments who do not show developmental impairments they will show at a later age. Many of these children will be found disabled. There are many conditions where we know at birth that a child is going to be disabled. Such children should not be required to wait for SSI services until disease has sufficient time to devastate the child's development.

Second, the childhood listings of impairment are age inappropriate, incomplete and unenlightened by current medical knowledge.

Third, no listing will ever reach all the children we believe the framers of this legislation sought to reach.

We recommend four routes by which children should become medically eligible for SSI. The first is that of established risk. Children with an established risk should be eligible by virtue of a diagnosis known to lead to disability. A child should not be required to wait until her or his developmental path has deviated sufficiently to establish a diagnosis through conventional tests, for example, many types of chromosomal problems or the more common Down's Syndrome.

The second route is that of biological risk. As an example, sick newborn children treated in a neonatal intensive care unit may not show early signs of a handicapping condition.

The third route is that of a functional assessment. Any child with a known or suspected disabling condition should be entitled to an assessment, including a medical diagnosis of health and health limitations, a description of major bodily functions and a delineation of familial and environmental competencies and limitations.

The fourth route would be qualifying under the revised childhood listings. In response to a question from your staff, the academy believes pediatricians should conduct the assessment of children. Pe-

diatricians, we feel, are the most qualified to diagnose and treat conditions which will lead to a disability and are usually the first professionals to identify high-risk children.

Finally, SSA has not fulfilled its legal or moral obligation. We feel the availability of supplemental security income to persons with disabilities is one of this country's best-kept secrets. Outreach activities should commence with already existing programs, including, for example, the comprehensive child find system of Public Law 99-457, the services for children with special health needs of the title V program, the early and periodic screening and detection program of Medicaid and the public school identification of Public Law 94-142.

The academy strongly supports H.R. 868. We will be happy to work with its sponsors toward its enactment, and we commend your efforts, Chairman Downey, at improving the access to needed health care for disabled children.

I have more extensive remarks, which we have already submitted.

Acting Chairman DOWNEY. Thank you. The statements in their entirety, will be in the record.

[The statement of Avrum L. Katcher follows:]

Statement of Avrum L. Katcher, M.D., American Academy of Pediatrics

Mr. Chairman, my name is Avrum Katcher, M.D. I am a practicing pediatrician from Flemington, New Jersey. I am a Fellow of the American Academy of Pediatrics, and a member of the Academy's Committee on Children With Disabilities. The Academy represents over 38,000 pediatricians in the United States who care and advocate for the well-being of infants, children and adolescents. I am also a clinical professor of pediatrics at the Robert Wood Johnson Medical School in New Brunswick, New Jersey, and am on the staff of the Hunterdon Medical Center in Flemington, New Jersey.

The Academy strongly supports H.R. 868, the "SSI Disabled and Blind Children Act of 1989" which you and Mr. Matsui have introduced. You are to be commended for your leadership. If enacted, this important legislation will correct many of the inequities in the children's portion of the Supplemental Security Income Program. As we are all acutely aware, despite its promise, the SSI program reaches only one quarter of all disabled children living at home below the poverty line. While all the reasons for low enrollment are unknown, several are clear. First, the childhood listings are overly narrow and do not reflect current medical knowledge of disease processes in terms of the various stages of childhood; second, the "comparable severity" standard for determining disability does not allow a functional assessment for children and is thus significantly more restrictive for children than adults; and finally, children with certain genetic or congenital impairments which lead to a disability are currently excluded from the program.

My testimony today will address each of these issues.

I. INDIVIDUAL AGE APPROPRIATE FUNCTIONAL ASSESSMENT

One of the major shortcomings, if not discriminatory aspects of the children's SSI program, is its failure to allow a functional assessment when determining a child's eligibility. Under the SSI regulations adults are considered to be disabled if their disability matches one of the listed medical impairments; if they can demonstrate a "medical equivalent" to one of the listed impairments; or if they can present all "material facts" -- such as age, education, work experience -- to demonstrate an inability to engage in substantial gainful activity. Children, however, are only allowed to establish eligibility through the first two criteria; either they qualify under the medical listing of impairments or suffer from a condition that is "medically equivalent" to the listed impairments. Unlike adult determinations, the Social Security Administration (SSA) will not consider non-medical criteria, such as the child's age, education, and most importantly, functional limitations in determining disability. Children with such disabling conditions as cystic fibrosis, Down syndrome or juvenile diabetes are not automatically eligible for SSI. To qualify, the child's condition must comply exactly with a long list of specific criteria. The child with juvenile diabetes who is insulin dependent but has not been hospitalized, subject to impaired renal function or growth retardation, does not meet the exact listing and will not be considered qualified.

To answer this problem, I think we need to look at a basic principle of childhood: for a child, the activities of daily living are the equivalent of an adult's ability to work. In still more fundamental terms, the work of a child is to grow -- grow physically, grow mentally, grow emotionally, grow in many ways -- until that child becomes a competent and loving adult who has been integrated into the community where that person dwells. And since a child is not an adult, that needed growth process must be nurtured by the family, and ultimately in our society by the community at large. During this maturation process, a child acquires a wide and continually differing range of capabilities. Therefore, special assessment criteria should be established for infants and toddlers, preschool children, primary school children, and adolescents.

The absence of functional criteria has inappropriately excluded many children from the SSI program -- children who suffer from physical impairments which directly interfere with their ability to function at an age appropriate level -- but who do not meet the strict medical criteria. Unfortunately, examples of such cases are numerous: (a) an adolescent with mental retardation was excluded from the SSI program because his IQ score was 13 points higher than the listings permitted -- this despite the fact he could only work in a sheltered environment and could not be gainfully employed; (b) the well-known case of Brian Zebley, a four-year-old child who was born with brain damage manifested by spastic right hemiparesis, mental retardation and a long list of disabling of conditions, who was denied SSI coverage; or (c) a child who suffered from an abnormal backward curvature of the spine which measured 74 degrees instead of the 90 degree curvature required to qualify by SSA. All suffered a serious impairment, all were significantly limited in their ability to perform age appropriate activities of daily living and all were denied SSI coverage.

Clearly an individual age-appropriate functional assessment should be undertaken to make a determination of a child's eligibility for SSI services. An assessment of function is an assessment of the child's ability to accomplish activities of daily life. A functional assessment must demonstrate whether the combination of the child and family environment is able to achieve the needed growth and take into account the degree and extent of medical support and intervention required to perform activities of daily living. Therefore, a functional assessment must consist of a thorough evaluation of biological, cognitive and emotional functions of the child, and an appraisal of the social environmental support available. Specifically, such an assessment should include a medical diagnosis of health and health limitations, a description of major bodily functions such as but not limited to, communication, mobility, special senses, cognitive skills, affective relationship capacity, and a delineation of the familial and environmental competencies and limitations which might offer significant assistance or hindrance to attaining a full role in society.

Depending on the child's condition, a functional assessment may require the participation of a multidisciplinary group, including pediatricians, psychologists, therapists, nurses and other professionals experienced and competent to evaluate children with disabilities. This process should be led by a pediatrician. As primary care physicians, pediatricians are experts in the child's total condition and are trained diagnosticians.

II. PRESUMPTION OF DISABILITY

Currently, SSA refuses to make a finding of disability in very young children with genetic or congenital impairments who do not yet show the developmental deficits they will show at a later age. Beyond a doubt many of these children will ultimately be found disabled, yet SSA refuses to qualify them until they meet the medical criteria. In the meantime, parents are deprived of financial and medical support which would help the child develop to his or her fullest capacity. The Academy believes that children with documented severe genetic and congenital diseases (i.e., Down syndrome, spina bifida, cystic fibrosis, congenital heart disease, chronic renal failure), should be certified as disabled at the time a diagnosis is made. Such children should not be required to wait for SSI services until the disease has sufficient time to exert a devastating measureable effect upon the child's development.

III. CHILDHOOD LISTINGS OF IMPAIRMENTS

The childhood listings of impairments are inappropriate on several counts and should be overhauled.

Published in 1977, the listing of childhood impairments is not complete and does not reflect current medical knowledge. Many childhood conditions, such as Down Syndrome and a variety of metabolic disorders, are not included. Moreover, the list has not been updated since its original publication in 1977. A number of the listings contain inappropriate and inaccurate medical criteria, such as the use of outdated laboratory and clinical findings.

Second, the listings do not comprehensively describe the functional limitations associated with childhood. Many of the listings make no reference to medical factors which relate to the physical, mental and emotional development of a child. Nor are the listings age appropriate. The Social Security Administration cannot adequately evaluate the severity of functional limitations without the establishment of different criteria that correspond to different stages of maturity. These include infants and toddlers, preschool children, primary school children and adolescents.

Finally, the listings generally do not describe disease processes in terms of the various stages of childhood. In particular, diseases of infancy raise difficult evaluation problems, distinct from those presented by the older child, and should be evaluated differently, for example Wernig Hoffmann disease or muscular dystrophy.

As the legislation recommends, revision of this list needs to take place in a timely fashion. The Academy is eager to assist the Secretary with this process.

Clearly no listing will ever reach all the children we believe the framers of this legislation sought to help. As the previous comments suggest, there should in essence be four routes by which children may become medically eligible for SSI. (The term "medically eligible" is used to distinguish information about the nature or extent of a child's disability from information about financial characteristics of the child or family, which should also be determining facts in reaching a decision on eligibility.) A child should be considered medically eligible by any one of the four categories.

Route I: Established Risk. Children with an established risk should be eligible by virtue of a diagnosis which is known to lead to a functional state of disability, such that as an adult the individual would be eligible for SSI. A typical example would be the child with Down Syndrome. This diagnosis may be established at birth or shortly thereafter. Many of the complications which create disability occur in infancy. The most common examples are congenital heart malformations which may produce heart failure or require surgery, or immunodeficiencies which produce recurrent infections. Even if such serious disorders are not present, it is established that such a child will, with a probability exceeding 99 percent, be mentally retarded and in need of special support in order to function at an optimum level. Such a child should not be required to wait until his or her developmental path has deviated sufficiently from the norm to establish a diagnosis of retardation through conventional tests. It flies in the face of reason to deny help when it is most needed.

Another example is the child with spina bifida. This may be diagnosed prior to birth. In almost all instances surgery is required shortly after birth. Major complications of the motor system, the urinary system and the bowel, as well as the central nervous system, are likely to produce disability. It is not logical to wait to offer the help needed to enable the child to attain as much as possible of the child's potential endowment.

Route II: Biological Risk. Many premature or sick term newborn children are treated in a neonatal intensive care unit. During and after treatment it may not be possible to determine if the child has a condition which is handicapping. However, either the condition -- which led to the treatment in the intensive care unit -- or known complications, in some instances lead to residual damage. As examples, a child with neonatal meningitis is often at risk of hearing disability or central nervous system disability. A very low birth weight premature infant may have an intraventricular hemorrhage, such that brain damage is possible but not determinable for months afterwards. These children are at-risk. This risk is biological, but the extent of the problem is not clear in early life. If the child has been left with a learning disability, this may not be well defined until school age even though help is available from infancy on in the form of early intervention programs. We should be prepared to make available to these children every useful form of help. The enormously influential studies carried out in the state of Hawaii clearly show that these children at biological risk have much better outcomes if they are helped early, and if their environment is a supportive, interactive and stimulating one.

Route III: Functional Assessment. Regardless of whether either of the risks described above are present, any child with a known or suspected disabling condition should be entitled to an assessment of function. Such an assessment would include a medical diagnosis of health and health limitations, a description of major bodily functions such as, but not limited to, communication, mobility, special senses, cognitive skills, affective relationship capability, and a delineation of the familial and environmental competencies and limitations which might offer significant assistance or hindrance to attaining a full role in society. This assessment should be carried out by a multidisciplinary team, with involvement of health, social, educational and behavioral specialists, and should always include input from a pediatrician.

Route IV: Childhood Listings. Any child who qualifies under a revised childhood listing, or who has a condition of comparable severity, would qualify for SSI.

IV. ROLE OF THE PEDIATRICIAN IN CONDUCTING ASSESSMENTS

In response to your request as to whether the SSA should require a pediatrician to conduct the assessments of children, the Academy believes such a requirement would be wise, for the following reasons. Pediatricians are the experts in child health care, and are the most qualified to diagnose and treat conditions which will lead to a disability. Pediatricians and other physicians are usually the first professionals to identify high-risk children, particularly from birth through the toddler years, and are the only professionals licensed to conduct medical evaluations and make medical diagnoses. Parents who are concerned about the development of a child frequently first discuss their concerns with their pediatrician. Parents often seek help from their pediatricians for appropriate diagnosis, and recommendations for care and referral to suitable therapy programs. Pediatricians also are able to assure that diseases are not concurrently present. For example, children with hypothyroidism, absence seizures or severe attention disorders -- relatively common conditions which can potentially be treated -- may be inappropriately labelled as having developmental delay if not diagnosed by a physician.

A pediatrician is also in an ideal position to:

1) first identify disabled children or those at-risk as early as the newborn period;

2) participate as a member of a multidisciplinary team, when such teams are necessary, that would perform functional assessments;

3) help assess the interactions between the infant and the family over time; and

4) provide necessary health care services on a broader basis.

As you know, children differ from adults physically, metabolically and emotionally. Children react differently to stress, metabolize drugs differently and suffer from different diseases and injuries than adults do. The special expertise of a pediatrician is best suited to evaluate a child's health care needs. For the purposes of an assessment, pediatricians are most qualified to deal with a child's emotions, behavior, growth and development.

Pediatricians currently include evaluation for disability and developmental delay of infants and toddlers as part of their comprehensive well-child health care. The Academy has aggressively educated its members on the special needs of children with disabilities and will continue to do so. For all of the above reasons, we recommend that the SSA be required to use pediatricians when the assessment of a child is needed.

V. IMPROVING OUTREACH

No child can be helped unless identified. The Academy does not believe the SSA has fulfilled its legal or moral obligation to find children in need of help. The availability of SSI to persons with disabilities is one of this country's best kept secrets. The SSA should commence active outreach endeavors. Outreach activities should be directed to persons and places where disabled children are specifically evaluated and treatment is provided. This need not be done by by creating a new outreach service, but by the simple and effective method of building on the outreach of other, already existing programs. Several that I have in mind include the Comprehensive Child Find System of P.L. 99-457, the Services for Children with Special Health Needs of the Title V Program, the Early and Periodic Screening, Detection and Treatment Program, and the public school identification programs of P.L. 94-142. Each of these has generated large lists of handicapped children. I suggest that SSA obtain these lists, reach out to those who are both on the list and in the potential economic brackets to be helped, and start with these lists as a basis for a working population to be assessed for inclusion as disabled under the SSI definition.

Further consideration should be given for outreach efforts to include other established programs that come in contact with at-risk children. Nutritionists participating in the Supplemental Food Program for Women, Infants and Children (WIC) see many children whose only contact with the system is through this program, although WIC covers only half of the children who need it. Head Start is another program that could alert families to the SSI services. And certainly child care centers should be utilized as an important information resource.

Conclusion

The Academy strongly supports H.R. 868 and will work with the sponsors towards its enactment. In addition, the Social Security Administration should mount a training program to adequately prepare professionals to evaluate and certify eligibility for SSI, as well as increase public awareness of the availability of the program. Chairman Downey, the American Academy of Pediatrics commends your efforts aimed at improving the access to needed health care for the population of disabled children across our country. Thank you.

Acting Chairman DOWNEY. Ms. Holle.

STATEMENT OF MARILYN HOLLE, SENIOR ATTORNEY, PROTECTION & ADVOCACY, INC.

Ms. HOLLE. Good afternoon, Congressman Downey. I am a senior attorney with Protection and Advocacy in Los Angeles and I am here to bring you the experiences of California disabled children including the experience of children with spina bifida.

The first problem we see that the children encounter in establshing disability is the fact that the listings are incomplete. They miss significant factors.

For instance, nowhere in the listings do you consider the criterion of a tracheostomy. That is despite the fact a recent study by the University of California at San Francisco indicates that 10 to 40 percent of children under the age of 1 year going home with a tracheostomy do not live a year.

In addition, the listings do not address feeding problems: Children who need to be fed through a gastrostomy tube, who require nasal-gastric tube feeding or who have other slow and difficult feeding problems.

Both of these factors, I might note, are factors which may entitle you to placement in a skilled nursing facility or a Medicaid funded facility. You can be eligible for such placement but not eligible for SSI because of those very same handicapping conditions.

The listings are also inadequate with respect to many of the disability problems that are related to neurological and cognitive impairment. For example, the childhood listing 112.05B for mental retardation requires a full scale IQ of 59 or below. It does not permit looking at subpart or other discrepancies, does not let you look at problems that flow from the uneven effect of such prenatal factors as drug exposure or premature birth or risk, say, from brain infections, et cetera, which may impact cognitive functioning but may not impact cognitive functioning globally or uniformly. In such cases, looking at only the full scale IQ does not capture the degree of disability.

The listings also limit how a combination of impairments which includes cognitive deficits can be looked at. In fact, the only route for looking at a combination of impairments which includes cognitive deficits is through listing 112.05C. To meet listing 112.05C you have to show a full scale IQ of 60 to 69, plus someother significant impairment.

If your full scale IQ tests at 72, you are out of the ballpark even if you have other significant impairments. The listings are inadequate also because of the fact of Social Security Ruling 83-19 which requires equal determinations which are totally out of sync with any commonsense understanding of what equivalence might mean. Under Social Security Ruling 83-19 you must pick out a cluster of criteria in one listing and combine it with criteria from another listing. It doesn't work if you have a problem that doesn't fit.

But even if the listings are fixed, I really don't think it is going to address the needs of children who are not easily plugged into the listings criteria. We see all the time children who just don't fit in,

whose combination of impairments, particularly from insults before or after birth to the neurological system, create a whole range of problems that are not easily catalogued if you look at the discrete criteria in the listings.

Mr. Enoff addressed his concerns about the presumption aspect of the bill. Let me address a couple of those concerns.

First, it is my understanding that H.R. 868 provides for a presumption which is rebuttable, not conclusive. Second, when you look at something like spina bifada, for instance, I would agree that perhaps a child with occult spina bifida, that is without the open spine aspect, might be someone to whom the presumption might not apply. H.R. 868 simply creates a situation where you give that young child the benefit of doubt unless you show that it is not likely this child is going to be disabled under SSI standards later on.

In addition, Mr. Enoff mentioned the medical improvements standard as being a reason why you should not extend SSI eligibility to these severely disabled toddlers and infants. Frankly, the medical improvements standard would not apply because you would be going from one standard under age 4 to a different standard over age 4. So I don't think that you even need to reach that.

I think the best way to understand the draconian character of the standard for looking at infants is to look at listing 110.08. Under that listing, in order to qualify at birth you must show that it is a surprise you survived the womb or it is clear your disability is going to be so severe that you will never make it up to a 2-year-old functional level.

Beyond that, listing 112.05A, which applies to infants and toddlers too young for an IQ test, requires a 50-percent discrepancy in developmental milestones. That means infants and toddlers have to be more severely disabled, significantly more disabled, than would be a child over the age of 4. That is because, in effect, a 50-percent discrepancy is equivalent to an IQ of about 50 in an older child, say, in a 10- or 12-year-old. But listing 112.05A is more restrictive than that because the milestones have to be across the functional spectrum. You are looking at not only aspects of cognitive functioning, but also motor functioning. In effect, you are requiring a toddler or infant to function at below an IQ of 50 and have the additional significant impairments in addition to cognitive impairments. Compare this with listing 112.05C which says you qualify with an IQ of 60 to 69, plus an additional significant impairment.

A presumption system would include children, who once they get past age 4 and into childhood, would in fact qualify for benefits. H.R. 868 would allow such children access to health care needed for their disability and needed to support family integrity.

Another reason for the importance of the disability standards is access to disability linked Medicaid in those States having an optional program. In looking at just California, for instance, the single mother of a disabled child can earn about $1,500 a month before there is any Medicaid share of cost, but if that child were only to be covered by AFDC-linked Medicaid, the share of cost would be about $500, $560, a difficult barrier, particularly for a child whose health care needs are chronic and severe.

Additionally, Medicaid for that severely disabled child might not be available if the family were intact and, therefore, some of the eligibility factors of AFDC were not present.

Finally, the National Council on Independent Living is not here with you today and they have asked me to convey to you their support for H.R. 8 and particularly those aspects that would enable disabled folks to transition from title II disability benefits to work.

The independent living movement has worked with the President's Committee on Handicapped and other groups to get employers to tailor jobs to mesh with the disability limitations of severely disabled receiving title II and title XVI disability benefits. Their efforts and the opening up of employment opportunities is often times frustrated by the failure to provide work incentives that are meaningful for long-term disabled in the title II disability programs.

In addition, the provisions in H.R. 868 which clarify some of the section 1619 provisions are very important for removing the barriers to employment—employment that the independent living movement has worked so hard to open up. They would like more of the severely disabled to be able to take advantage of employment opportunities.

Thank you.

[The statement of Marilyn Holle follows:]

Statement of Marilyn Holle, Protection and Advocacy, Inc.

I am an attorney with Protection & Advocacy, Inc., a nonprofit corporation established in 1978 under the federal Developmentally Disabled Assistance and Bill of Rights Act (Pub.L. 94-103) to protect and advocate for the rights of Californians with developmental disabilities -- i.e., persons of any age who become chronically and severely disabled prior to the age of 22. In addition, Protection & Advocacy, pursuant to the Protection & Advocacy for Mentally Ill Individuals Act of 1986 (Pub.L. 99-319) advocates for Californians identified as mentally ill who are in or have been in a facility providing care or treatment.

Through my work I have assisted and am assisting many severely disabled children as they try to establish that they meet the SSI disability criteria. PAI provides direct assistance and representation to severely disabled children. We assist children indirectly through technical assistance to professionals such as to social workers and doctors in Children's Hospitals, to other attorneys including those in legal services programs as well as those in private practice, and to community based advocacy groups such as the Spina Bifida Association of Greater Los Angeles. Congressman Matsui requested that PAI bring to him and you information about the difficulties developmentally disabled children encounter in establishing that they meet the SSI disability standards. I am here to share with you the experiences of California developmentally disabled children.

(1) **The Child Listings ignore significant disability factors often found in severely disabled children.**

The gaps in the current Child Listings become apparent when one compares the cases of individual children against the Listings of Impairments[1/] to find Listings criteria which might apply to them. For instance, studies of children who are discharged with a tracheostomy from the hospital when they under the age of one year show a mortality rate ranging from 10-40% in the year following discharge.[2/] The listings do not consider tracheostomies. Tracheostomies are not considered even though having a tracheostomy imposes significant health risks. Tracheostomies also impose significant limitations on activities of daily living, and a child with a traecheostomy usually requires intensive support to remain at home. Further, having a tracheostomy is one of the indices of a need for skilled nursing care and placement in a skilled nursing facility.[3/]

1/Part B of Appendix 1 to Part P of 20 CFR Section 404.

2/"Tracheostomy in Children with Emphasis on Homecare," Duncan, Howell, deLorimier, Adzik, Harrison (University of California at San Francisco), accepted for publication by the Journal of Pediatric Surgery late 1989 or early 1990.

3/42 CFR § 409.33(b): "Services that qualify as skilled nursing services. ... (3) Nasopharyngeal and tracheostomy aspiration." See, also, 42 CFR § 440.170(d) which incorporates § 440.40 and §§ 409.31 through 409.35.

Tracheostomies are surgical openings in the neck through which a child breathes and through wich excess fluids are extracted (suctioned) to prevent aspiration or formation of mucous plugs which could cut off breathing.[4] Usually children with tracheostomies have to be closely monitored to identify the signs and symptoms indicating a need for intervention.[5] They usually also require pulmonary toiletting.[6] Finally, because a child with a tracheostomy does not have the advantage of a nose to moisten air and trap dust, there are environmental limitations on where the child can go and what he can do.

The Listings also ignore the range of feeding problems PAI staff have seen in our developmentally disabled clients, problems which require intensive support and which limit activities of daily living. Because of problems in swallowing, problems in esophagus peristalsis, problems with reflux and the aspiration of food and fluids into the lungs, many of our clients require specialized assistance in order to receive nutrition -- as through a gastrostomy, through a nasal-gastric tube, through feeding in accord with specific protocols. A gastrostomy[7] is a surgically implanted tube into the stomach. Even more difficult in terms of potential risks and the need for intensive support are those who require feeding through a nasal-gastric or Levin tube or who require slow feeding with intensive monitoring and correct positioning. Feeding with a nasal-gastric tube requires the insertion and removal of a tube through the nose, down the throat and into the stomach. Children who require feeding in accord with a specific protocol are children who have to be fed slowly and carefully over a time period taking often an hour and a half or more per feeding. Afterwards they typically have to be positioned correctly to minimize the risk of food refluxing from the stomach up and into the lungs.[8]

In the mental impairment area the Listings ignore a range of problems PAI staff frequently see in our developmentally disabled clients. The Listings ignore autism and its unique pattern of symptoms where the autism is not coupled with mental

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[4]/The frequency of the need for suctioning varies from as often as every five to ten minutes to once every other hour.

[5]/A doctor with whom we work at Rancho Los Amigos Hospital in Los Angeles County reported that one of her clients with a tracheostomy who was in a nursing home died when a mucous plug blocked off her breathing during a 15 minute period when she was not under direct observation of nursing staff.

[6]/Pulmonary toiletting is a procedure which involves placing the child in a downward slant and percussing each of the eight lung lobes to loosen secretions. The need for pulmonary toiletting varies from once or twice a day to every three hours. Failure to provide proper pulmonary toiletting and timely suctioning can result in aspiration pnuemonia.

[7]/Having a gastrostomy or needing feeding through a nasal-gastric tube also is an indice of the need for skilled nursing care and SNF or ICF placement. 42 CFR § 409.33 (b): "Services that qualify as skilled nursing services. ... (2) Levin tube and gastrostomy feedings." See, also, note 3 above.

[8]/One of my clients whose feeding difficulties were related to a cleft palate went into full cardiac arrest with consequential brain damage when food aspirated into his lungs. Apparently the neonatal intensive care nurse failed to properly position the child following the feeding.

retardation which meets the Listings criteria.[9] In one case, which is still pending, the State Disability Evaluation Service[10] explained to the mother of a three-year-old severely autistic child that not only did her child's disability not meet the Listings, but also that the child's disability did not meet the 12-month duration rule[11] because of expectations of improvement.

The Listings ignore significant disability groups as well. For instance, the Listings ignore the pattern of symptoms associated with tourettes syndrome -- involuntary tics and vocalizations. The Listings do not address the symptoms associated with severe hyperactivity and/or severe attention deficit disorders, disabilities which require intensive support and intervention.

(2) **Improvement and updating of the Listings, however, is no substitute for individualized assessments which consider the combination of a child's disability impairments and the functional impact of those impairments, and consider how the disability impairments interfere with age appropriate activities of daily living, including the degree of support and intervention required in order to perform such daily living activities.**

Under Title XVI of the Social Security Act, Social Security cannot rely on the Listings alone, even if improved, to determine whether a child meets the SSI disability standards. Any question about Social Security's obligations were resolved by the 1984 Amendments to the Social Security Act[12] requiring the Social Security Acministration to consider an applicant's or recipient's combination of impairments at all stages of the application and review processes. Improvement of the Child Listings is important because the Listings permit preliminary screening without the need for a full individualized assessment in the case of individuals who meet or equal the Listings.[13] However, such improvement cannot substitute for the right of each severely disabled child to be looked at as an unique individual -- just as every severely disabled adult has a right

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9/Regarding mental retardation, the Child Listings require that the full-scale I.Q. testing -- that is the combination of the performance and verbal subparts of the test -- measure 59 or below to qualify. Listings 12.05(B). This contrasts with the Adult Listings which indicate that the Listings are met if the full scale or the performance subtest or the verbal subtest measure 59 or below. Listing 12.05(B). As discussed below, the Child Listings exclude a severely disabled segment of children whose cognitive limitations are not global.

10/Social Security contracts with the state to make the initial determination of disability for applicants of both SSI and Title II disability benefits and, should there be an appeal, the determination decision as well. See 20 CFR Subpart J.

11/Part of the disability standard is the durational one: The disability must be one "which can be expected to result in death or which has lasted or can be expected to last a continuous period of not less than 12 months." 20 CFR Section 46.905(a).

12/The Social Security Disability Reform Act of 1984, Pub.L. 98-460, adding 42 U.S.C. § 1382c(a)(3)(G).

13/Bowen v. City of New York, 106 S.Ct. 2022, 2025 (1986); Bowen v. Yuckert, 107 S.Ct. 2287, 2297 (1987).

to be looked at as an unique individual subsequent to a determination that he or she does not meet or equal the listings.

The Third Circuit's opinion in Zebley[14/] correctly defines the application and procedural rights of children under current law. The Social Security Administration, however, refuses to look at each child individually, refuses to look at the functional impact of the combination of impairments, refuses to look at the impact of the child's impairments on age appropriate activities, and refuses to look at the degree of support and intervention the child requires because of the disability impairments. It is important, therefore, that Congress underscore the right of children to have their entitlement to SSI benefits considered in light of their unique combination of functional limitations and how those functional limitations impact them.

In addition, Congressional action to underscore Social Security's obligations is important to overcome the chilling effect of current practices. Medical social workers and counselors know the Social Security rules for children. Based on this knowledge they make decisions as to which children should apply for SSI and which children's cases are too complex or unusual to fit into the Listings' criteria. Spelling out Social Security's obligation to severely disabled children would go a long way toward improving outreach because, from my experience, many children would no longer in effect be denied before they even apply.

An example of children who often require individualized assessments because they do not fit neatly into the criteria for a particular Listing (i.e., do not "meet" a Listing) or do not fit neatly into the criteria for a couple of Listings (i.e., do not "equal" the Listings) are children who have suffered neurological injury through a variety of causes: through exposure to lead, through premature birth, through prenatal exposure to drugs, etc. Typically these childrens will have somewhat delayed motor development, poor coordination, hypersensitivity to noise, attention deficit and/or hyperactivity problems, cognitive problems which do not manifest in global retardation and which may not be measurable except by neuropsychological assessments. The rigidity of the Listings can be seen by looking at Listing 112.05(C) which defines and limits how cognitive impairments are considered in conjunction with other impairments. Under 112.05(C), an individual qualifies if he or she has an

> IQ of 60-69, inclusive, and a physical or other mental impairment imposing additional and significant restriction of function or developmental progression.

Excluded, of course, are children who test above 69 but who have severe cognitive deficits in specific areas which are not measured or captured by the full-scale I.Q. or even the verbal or performance subparts of the I.Q. test. The severe cognitive deficits include problems in such areas as memory, ability to process information received visually or aurally, follow directions involving more than one or two steps, etc. For them other impairments cannot be considered. For them, absent an obligation for individual assessments which look at the whole

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14/ Zebley v. Bowen, 855 F.2d 67 (3d Cir. 1988), cert. granted ____ U.S. _____ (5-15-89).

child, the 1984 Amendment requirement to consider a combination of impairments does not exist.

Other factors which properly should be considered in individual assessments include

-- environmental limitations -- dust-free environment, regulated temperature for children with impairments in their internal ability to regulate body temperature, avoidance of sun, etc.

-- level of supervision and monitoring required because of a disability impairment -- for instance, for children with Prader-Willi Syndrome,[15] one-on-one supervision is required to prevent them from excess eating or escaping to eat; for children with severe attention deficit and/or hyperactivity problems, close monitoring and intervention to keep them on task is necessary; etc.

Finally, the theoretical availability of establishing eligibility by showing that you "equal" listings is no remedy for individualized assessment. First, as will be explained by others testifying, Social Security Ruling 83-19 rigidly limits how you can establish that you meet the "equal" criterion. Essentially you have to package together specific Listing criteria in order to meet the "equals" criterion -- something that does not work given the unique disability patterns of many children. Second, the "equals" criterion is decreasingly and infrequently used by Social Security itself.[16] Third, pointing out how someone "equals" the listings is beyond the capabilities of a lay person since the operational definition of "equals" under SSR 83-19 is at odds with any commonsense understanding of what "equals" means. While I like other sophisticated advocates can come up with arguments about why someone "equals" the listing under the strictures laid out in SSR 83-19, a layperson realistically cannot do that. The system should not require advocates and attorneys for access to the Social Security system. Involvement of attorneys and resort to appeals should be limited to instances when a fair system does not work in an individual case. We should not be required in the regular course of the application process to insure fundamental fairness.

15/Prader-Willi Syndrome is characterized by an uncontrollable and pathological compulsion to eat. In homes where there is a child with Prader-Willi you usually will find that the refrigerator and cabinets containing food have been locked. I.Q. scores typically are inversely related to weight -- the more obese the child, the lower the I.Q. scores and vice versa.

16/Available Title II statistics indicate that of the total Title II disability approvals, from 1975 to 1978 40-45% were on the basis of "equaling" the listings and 29-34% on the basis of "meeting" the listings. 99th Cong., 2d Sess., Committee on Ways and Means, WMCP 99-14, "Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means," Table 2 (March 3, 1986), Attachment 7, p.2. By 1980 when the policies embodied in SSR 83-19 became effective, "meets" exceedeed "equals" by 57.9% to 16.2%. From 1982 through 1985, "equals" determinations were only 8-9%. Id. It is our understanding that current statistics on children who qualify based on an "equals" determination do not exceed 8%.

(3) **Children under the age of four who have severe cognitive and other neurological impairments are unfairly treated because they must be more severely disabled than their counterparts over the age of four in order to meet the SSI disability standards.**

The unfairness of the Listings to severely disabled children under the age of four can be seen by looking at a couple of the Listings. For an infant or newborn with a congenital disorder to qualify, you must show either that it is a surprise for the child to be living outside the womb or, if he survives, that he will not develop beyond the two-year-old level:

> 110.08 Castrophic congenital abnormalities or disease. With:
> A. A positive diagnosis (such as anencephaly, trisomy D or E, cyclopia, etc.) generally regarded as being incompatible with extrauterine life; or
> B. A positive diagnosis (such as cri du chat, Tay-Sachs disease) wherein attainment of the growth and development level of 2 years is not expected to occur.

Listing 110.08 is patently a draconian standard.

For severely developmentally disabled children who are not yet at an age where their I.Q. can be tested, Listings 112.05(A) requires that you show

> Achievement of only those developmental milestones generally acquired by children no more than one-half the child's chronological age.

In looking at children under the age of 4 years, and looking at who you reach in terms of standard deviations from the norm, children have to be much more severely disabled under the age of four than above that age to meet the Listings. That is because requiring a 50% delay differential reaches a significantly smaller percentage of children than is reached by using a 59 I.Q. The younger a child is the more severely disabled he or she would have to be to meet the 50% differential criteria.

I.Q. scores use chronologicval age in relation to mental age to produce a numerical score. For instance, a 12.0-year-old child with a mental age of 6.0 years would have an I.Q. of 50 (dependent on the weighting of the particular test). An I.Q. of 59 or less is all that is required for SSI eligibility in an older child. An I.Q. of 59 represents an approximate 40% discrepancy between chronologicval and mental age. Developmental milestones are reported in ranges of ages in which skills are generally mastered. For instance, two-word utterances usually occur in chilren between 18 and 30 months of age. If 30 months were used as the benchmark, a child would have to be 5 years old to meet the 50% criteria. Using a ratio of chronological age to mastery age, requiring a 50% developmental discrepancy is analogous to requiring young children to have an I.Q. of 50 or below while older children need only show an I.Q. of 59 or below.

Further, developmental melestones measure both cognitive functioning and motor skills and therefore test a broader scope of impairments than does the I.Q. test. Looking at the discrepancy in developmental milestones with respect to motor skills, in effect the applicable comparison is not 112.05(B) and its requirement of an I.Q. of 59 or below, but rather the Listing 112.05(C) criteria of an I.Q. of 60-69 coupled with "a physical ... impairment imposing additional and significant restriction of function or developmental progression." A young child, therefore, has to show an I.Q. equivalent to 50 in an older child <u>plus</u> additional severe developmental delays.

(4) The SSI disability standards for children are critically important to severely disabled children in need of ongoing medical assistance even if they would not qualify for SSI cash benefits because of family income.

We are frequently called by families with a severely disabled child who has been excluded from the family's group health insurance plan because of the disability. This happens when a parent changes jobs and when the employer changes health-care plans. Indeed the employers' change of health care plans sometimes appears to come about because of high rates linked to the disabled child's inclusion in the prior health care plan. Under the COBRA requirements, of course, the prior coverage is extended for a limited period of time. But following the expiration of the COBRA extension, the disabled child is left without health care coverage at all, a particularly frightening circumstance for families where the child has chronic health care needs.

Medicaid (Medi-Cal) may be the only health care protection option available to excluded disabled children in states which have elected to provide Medicaid coverage for children who do not qualify for SSI cash benefits because of excess family income.[17/] Provided the family met the SSI resource limitations and the child met the SSI disability standard, the child would qualify for disability linked Medicaid subject to a share of cost contribution from the family. That same child might not qualify for AFDC-linked Medicaid because he or she is in an intact family. And the procedures for determining share of cost for an AFDC-linked Medicaid child and an SSI-linked Medicaid child differ so significantly that in reality Medicaid would not be available to the disabled child. Thus SSI disability standards are important not only for those children who need both cash assistance and health care coverage through categorically linked Medicaid, but also for those children who are denied health care coverage simply because of the chronicity and severity of their health care needs. They need health care coverage through optional disability linked Medicaid programs. Indeed qualifying for disability-linked Medicaid or a Katie Beckett waiver for those few states that make it avaible to severely disabled children and their familes, may be the only way to avoid out-of home placement for a severely disabled child with chronic health care needs.

17/ 42 CFR § 435 Subparts C, D and F. There are essentially two optional medically needy Medicaid (Medi-Cal) programs for children: One for children who meet al the eligibility requirements of AFDC except for excess income and one for children who meet all the eligibility requirements for SSI except for excess income. The primary practical difference between the two is how the two programs treat parental earned income. Under AFDC-linked Medically Needy Medicaid, after deducting earned income and certain other limited deduction allowances and the family support allowance based on family size, the balance is the share of cost -- that is, the amount which has to be paid or obligated to pay before Medicaid kicks in. Under disability-linked Medically Needy Medicaid, after deducting the earned and unearned income allowance the remainder is divided in two and the family allowance is then deducted from the remaining 50% to determine share of cost. In California, for instance, a single parent and a disabled child could gross about $1519 a month before being assessed a share of cost and the share of cost would be about 50% of the gross income above that. Under AFDC-linked Medicaid, however, the share of cost would be about $567 a month for the same family and the share of cost would be increased a dollar for every gross income dollar above that.

Acting Chairman DOWNEY. Ms. Mulligan.

STATEMENT OF KATHLEEN MULLIGAN, PRESIDENT, KAILEIGH MULLIGAN FOUNDATION

Ms. MULLIGAN. Good afternoon, Mr. Chairman.

My name is Kathleen Mulligan, and I have traveled here today from the Merrimack Valley town of Methuen in Massachusetts. My purpose in appearing here is to share with you the problems of families with severely disabled children that are personified by my 3-year-old daughter, Kaileigh. Kaileigh Mulligan was born with severe heart problems, serious stomach defects and Down's syndrome. She has survived open heart surgery and is fed through a gastrointestinal tube. Kaileigh spent the first year of her life at the Tufts New England Medical School Center in Boston.

The medical staff there confronted with high costs and hard choices placed sufficient value on her life to fight for her survival When they could have easily given up, they chose instead to continuously give of themselves.

When Kaileigh finally came home to us, my husband and I were the ones immediately faced with the costs and choices. Her Social Security benefits were discontinued and we were informed that they would only be reinstated if we placed Kaileigh in a pediatric institution, abandon her to a foster home, allowed her to be put in an adoptive home or got divorced.

In short, Kaileigh could only qualify for benefits if the family self-destructed. These are exceedingly cruel choices to give to any family.

They imply that the Government places a higher value on the bureaucratic system than on the survival of struggling and loving families. They also suggest to us, as her parents that the Social Security Administration believes Kaileigh would be better off without us.

The stark and simple message from the Social Security Administration was this: in exchange for any benefits for Kaileigh, we demand the custody of your child. Some things are not for sale. We made our choice, we kept Kaileigh.

In some respects that choice has been costly. The financial and emotional pressures we face have been staggering. The feeling of being alone has led us frequently to the brink of despair, what the Irish call "dark nights of the soul."

What continues to disturb us is the reality that the Social Security Administration penalizes us for having the very values one would think they would be interested in promoting. The benefit eligibility criteria persists in discriminating against intact families.

We are penalized for being responsible parents. That discrimination troubled people in my community to the point where they created the Kaileigh Mulligan Foundation in October of 1987. That foundation is of no direct benefit to our family but it does reach out to other families caught in the crunch between their urgent needs and the sometimes slow governmental response time.

That foundation also proudly stands as one community's affirmation that families such as ours have a place in America's kinder and gentler future.

The Commonwealth of Massachusetts has also been supportive through the creation of the Kaileigh Mulligan Home Care for Disabled Children Program.

This is a Medicaid income waiver program that permits a limited amount of families such as mine to receive insurance benefits for our severely disabled children.

Congressman Donnelly assumed the initiative to bring this issue to the attention of the legislative branch and my family acknowledges a debt of gratitude to him for recognizing a problem and independently seeking a remedy.

I should mention in all candor that our first approach was not to the legislative branch. Realizing that the Secretary of Health and Human Services had the authority to immediately upon a stroke of his pen correct this injustice, we met with Secretary Otis Bowen, M.D., last year.

The extent of his empathy was to coldly tell me, "You should feel fortunate, Mrs. Mulligan, your child is alive."

While, I continue to believe that the executive branch could and should shoulder the responsibility for correcting a problem they alone have created. I come to you today because they obviously lack the vision to recognize the existence of these children and their families.

I respectfully request that you support Congressman Donnelly's efforts to include us within a more inclusive and empathic society. My family, my community, my Commonwealth and Congressman Donnelly, understand that these children will continue being born regardless of what happens here today.

Our concern is for the length and the quality of the lives they will lead.

Finally, I want to underline that I am making this request as a proud parent who has made a choice and is prepared to live with the consequences. The price tag asked by the executive branch before they will provide benefits to my child is prohibitive.

Kaileigh Mulligan is not for sale and I thank you for this time today.

[The statement of Ms. Mulligan follows:]

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These are exceeding cruel choices to give any family. They imply that the executive branch of the federal government places a higher value on a bureaucratic system than on the survival of struggling and loving families. They also suggest to us as her parents that the Social Security Administration believes Kaileigh is better off without us.

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My family, my community, my Commonwealth and Congressman Donnelly understand that these children will continue being born regardless of what happens here today. Our concern is for the length and the quality of the lives they will lead. Join us, please. Help us, please. Lead us, please.

Finally, I want to underline that I am making this request as a proud parent who has made a choice and is prepared to live with the consequences. For the pricetag asked by the executive branch before they will provide benefits to my child is prohibitive. Kaileigh Mulligan is not for sale.

Thank you.

Acting Chairman DOWNEY. Thank you.
Ms. Elrod.

STATEMENT OF SUZANNE ELROD, MEMBER, COMMITTEE ON SOCIAL SECURITY AND MEDICAID, THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS

Ms. ELROD. Thank you, Mr. Chairman.

My name is Suzanne Elrod. I am a member of the Association for Persons with Severe Handicaps and a member of its Committee on Social Security and Medicaid.

TASH is an organization of over 8,000 parents and professionals who advocate for the rights of individuals with severe intellectual disabilities.

A large percentage of those we represent use the SSI system.

Social Security statistics published in February of this year show 21.4 percent of SSI recipients have mental retardation.

Unfortunately for these recipients as well as others, the system is ineffective.

TASH is resolved to allocating a great deal of its resources and energy to bring about positive changes in this system.

H.R. 866, H.R. 867, H.R. 868, H.R. 1525, and 71 address several TASH legislative priorities for this year.

The issues identified in your April 27 press release are of great concern to us: Children's disability eligibility, problems of those living in the household of another and the SSI benefit level and asset tests.

It is pretty difficult to address the SSI benefit level and asset test without talking about the longstanding concerns many share about substantial gainful activity.

SGA is an indirect, but highly related issue.

Some of our concern about the SGA issue was alleviated when the 98th Congress voted to make the provisions permanent.

However, SGA is very much an issue for those applying for SSI.

I had the opportunity to speak this month with the parent of a 20-year-old young man who has a pending application for SSI.

In his last year of special education, he has been given the opportunity to participate in a supported employment.

He will keep his job if it goes well.

The problem is even with part-time work, he is making just under $300 a month, SGA level.

His mom wants to know if this would jeopardize his pending application for SSI and the answer is yes, it would.

Her conclusion at this point is she will have to decide whether or not to encourage him to keep his job or to have him leave his job until such time as he is determined eligible for SSI.

He has moderate mental retardation plus ongoing physical and medical problems which limit his stamina. His potential to keep his job is unknown for those reasons, and he needs continuing medical care.

He cannot afford not to be covered by SSI and the accompanying medical assistance.

So when we support raising benefit levels which are now less than 75 percent of poverty, that is $368 a month for an individual,

it goes without saying that the SGA level of $300 a month clearly must be increased.

I would add that TASH is very much supportive of the provisions Representative Bartlett spoke about today in H.R. 8.

On to another benefit level issue: It may be interesting to note that the benefit levels differ sharply for those working adults who have a dependent with a disability depending whether he is a child or spouse.

Two persons with disabilities, if they should marry, are penalized by the SSI program, by $183 less per month than the total of their monthly benefits as single individuals.

I learned the other day of a couple who will have a June marriage ceremony which will include everything but the marriage certificate because of the SSI provisions in this regard. Something is dramatically wrong with this picture.

Also, related to the benefit level is the one-third reduction for persons living in their parents' home, people who, because of the severity of their disability can't afford to live anywhere else.

The one-third reduction defies logic.

Removing it would be one more tool to assure that persons with disabilities will have equitable chances to live independently and with dignity.

TASH also strongly supports H.R. 71, the Independent Trust and Families Contribution Act.

Current SSI rules that treat all contributions as unearned income discourage families that want to assist their adult sons and daughters with clothing, food and housing.

This practice truly thwarts family efforts to join government in providing for even basic standards of living for SSI recipients.

We urge speedy passage of this legislation.

Finally, we totally agree with the need, the serious need for reforming the rules pertaining to SSI eligibility for children.

The other witnesses today have very poignantly spoken to this issue, so I won't go into detail. It is included in more detail in our written remarks.

I do want to make a point of recognizing the value of the strong, continuing interventions that must start at birth with a child with severe disabilities and the support that the middle income fam[illegible] may need which they can't receive because they are not eligible for medical assistance.

This concludes my remarks.

TASH stands ready to assist the committee and its members in any efforts toward SSI improvements.

Thank you for holding these hearings.

[The statement and attachments follow:]

Statement of Suzanne Elrod, Association for Persons With Severe Handicaps

Mr. Chairman and Subcommittee members, please let me thank you for the opportunity to speak on behalf of The Association for Persons with Severe Handicaps (TASH) Committee on Social Security and Medicaid. TASH is an organization of over 8,000 parents and professionals who advocate for the rights of individuals with severe intellectual disabilities. Without the benefit of clear documentation, let me say that I would guess that a large percentage of what some folks call the TASH population are users of the SSI/SSDI system. According to SSA statistics published in February of 1989, 21.4 percent of the individuals receiving SSI have mental retardation. Unfortunately for individuals with severe intellectual disabilities, as well as other users, this system is not nearly as effective as it should be.

In 1987 and 1988 the Committee with TASH that is assigned the responsibility of Social Security policy issues thoroughly examined the SSI system as we now know it, and it was their determination at that time that a number of changes are needed. As a result, the following Resolution was adopted at the TASH Board in the fall of 1987:

WHEREAS, Serious inequities exist across Social Security programs affecting individuals with intellectual impairments, especially in SSI and SSDI, and

WHEREAS, Serious inequities exist in standards within programs administered by Social Security for populations with different lifelong impairments, and

WHEREAS, Serious inequities exist in the standards for Applicants versus Recipients in programs of the Social Security Administration, and

WHEREAS, SGA as a concept is outmoded, inadequate and inequitable at present levels for persons with intellectual impairments, and provides a serious disincentive to work, and

WHEREAS, Forthcoming Medical Reviews are not defined nor their ultimate effect known and they may present a serious problem for those attempting work even through Supported Employment, and

WHEREAS, Eligibility for the proposed Medicaid Home and Community Quality Services Amendments is limited to individuals who meet the eligibility requirements, SSI, and

WHEREAS, Many state programs have and will increasingly adopt Federal criteria (SSI eligibility) to determine eligibility for state-supported programs,

THEREFORE BE IT RESOLVED THAT TASH shall propose and/or support reform of present inequities through the elimination of the concept of SGA and/or the increase of SGA levels to reasonable and equitable levels for all programs, all populations and for applicants as well as recipients.

THEREFORE BE IT ALSO RESOLVED THAT TASH shall monitor the application of Medical Reviews and their effects on recipients with intellectual impairments.

AND BE IT FIANLLY RESOLVED THAT TASH allocate resources to effect positive changes in these programs.

(Originally adopted October 1987)

A close examination of these recommendations indicates strong TASH support of many of the SSI measures before the House this year. In fact, HR 866, 867, 868 and 1353 address a number of legislative priorities for this year.

The issues identified by this Committee in your April 27 press release are issues of concern to the field. SSI Outreach, children's disability eligibility, problems of those living in the household of others, the SSI benefit level and asset test -- I will address each of these briefly.

We of TASH have a long standing concern about the Substantial Gainful Activity (SGA) level for individuals who are receiving SSI. Let me add that this is just as true for individuals receiving SSDI, but since your interest is in SSI, I will limit my discussion to this program. Some of our concern about the SGA level was alleviated when the 98th Congress voted to make 1619 a&b permanent provisions of the Social Security Act. However, SGA is still very much an issue for persons who apply for SSI. There has been much talk about raising the current level of $300.00. Our clear recommendation to you is that you do so with all due speed. There are many reasons for this recommendation and these reasons go well beyond the fact that the current SGA level of $300.00 has remained static since 1979, despite significant and consistent increases in the consumer price index and the cost of living; even double digit inflation in some years; and (nominal) cost of living increases in SSI/DI benefits (please see attached graph).

I mention the Title II benefit here only to alert you that your concerns about SSI and any resultant improvements could be decimated in future years for persons with any severe disability which began in childhood. While those persons may receive SSI to begin with, if one of their parents dies, retires or becomes disabled, this SSI recipient will be converted to a Title II Disabled Adult Child beneficiary and will then face losing the benefits of all the congressional improvements to the SSI program because the Title II program has not been similarly improved. This has been and will continue to be a tragic occurrance for SSI recipients whose circumstances change drastically through no fault of their own and entirely outside their control.

Gaining and maintaining SSI for eligible individuals is additionally important when we look at other legislation being proposed to provide services and care to persons with severe disabilities in their own communities near family. Current Medicaid and long term care reform legislation in Congress has eligibility for those much needed and long overdue community services tied to SSI eligibility. Therefore, an unreal SGA level which prohibits persons with severe impairments from gaining SSI eligibility, keeps those same persons from receiving services in their community, surrounded by family and friends.

SGA represents an indirect, but highly related piece of information to be considered when looking at what needs improving regarding SSI benefit levels and the SSI asset test. In a more direct vein I want to again reinforce the fact that the current SSI benefit amount for an individual represents less than 75% of poverty level. Surely this fact alone is proof that benefit levels need to be raised. It is no surprise to all of you that recent years have seen serious cuts in various government subsidized housing programs which have typically been the only housing affordable for SSI recipients unless they were able to share housing with others. SSI benefit levels which fall below poverty level have seen our citizens who are most vulnerable having to live in the least costly, most substandard, most crime ridden neighborhoods in America - often those right in the heart of America's war on drugs. An increase in benefit levels can not magically cure this situation, but is would surely be one tool to help us assure citizens who have disabilities that they are not being relegated to urban ghettos simply because they have a disability.

This Committee may be interested to learn that benefit levels differ sharply for a working adult who has a disabled dependent depending on the relationship between that adult and the dependent. If the dependent is a child, the two person family is eligible for a higher rate of SSI than the two person family which is a married couple where one spouse is SSI eligible. Earnings are counted differently in these two cases, and create another serious inequity in the SSI program based on family relationship. In addition, should two persons with disabilities even consider the radical act of marriage, they are penalized drastically by the SSI program. Consider two persons who have severe cerebral palsy and use wheelchairs. It's not hard to imagine the expenses they might have above and beyond the typical expenses we all share. Individually, they are due 368 federal dollars in SSI. If they choose to avail themselves of the accepted American institution of marriage, they are due 553 federal dollars in SSI, $183 less than the sum of their individual benefits. For this reason, many SSI recipients feel they are being denied the right to marry based on their disability. Something is wrong with this picture.

Related to the benefit level is the one third reduction rule. I would challenge any of you to explain this policy to the parents of an adult with a severe disability, and to feel at the end of your explanation that it all made sense. To the contrary, it defies logic. First you tell the parents, whose son currently lives with them in their home, "Yes, your son is clearly eligible for SSI, but we're not going to give him a full benefit rate, because he lives with you. We're going to reduce his amount by one third." The parents then reply, "Of course he lives with us, he can't afford to live anywhere else." You respond with, "Well, when he can pay for his own apartment we'll increase his SSI benefit, but not until two months after he's in that apartment." The parents ask, "How can he even begin to pay his rent and buy groceries if his SSI is still reduced for the first two months - who can pay rent, utilities and buy food for $245/month?" You answer, "Well, keep him home then and have him pay his share of your household expenses. If he does that, we can also increase his SSI to $368/month." The parents tell you, "Well, his share of our household expenses is $325/month. How can he pay that if he only gets $245/month in SSI?" And so it goes, but it still makes no sense and it's still not equitable. Removing the one third reduction from SSI policy will again be one more tool to assure that persons with disabilities have the same opportunities we do to live independently and with dignity.

Finally, as I am sure you are well aware, the system of determining SSI eligibility for children with disabilities is in serious need of reform. The evaluation is limited to a narrow listing of impairments, or a disability that "equals" this narrow list. Children with very serious illnesses are completely eliminated from access to both cash benefits and the more important medical assistance. There is no consideration at all of a child's functional development and/or deficits. Children with Down Syndrome are typically denied SSI until 2 years of age or more because that's when infant IQ tests can demonstrate a lower IQ. There is no recognition of the strong, ongoing developmental interventions that must be implemented from birth to give this child the best shot at growing and developing. Nor is there recognition for all the extra hours parents must put in over and above those for the care and development of a typical infant. These parents grieve over the loss of the perfect child they envisioned, and then are denied benefits which could help support that child and ameliorate the disability. The Philadelphia Inquirer last November carried an article by Jonathan Stein, describing a number of shocking stories of children who were not considered severely disabled enough. Brian was one of the children Mr. Stein described.

> "Brian Z. of Delaware County was born brain-damaged, with partial paralysis and mental retardation. Brian has very limited gross motor skills, cannot judge distances and has such poor balance that he frequently falls down. By age 4 he had not yet achieved the development gains of a 2 year old."

There are equally unbelievable examples about children with serious disorders: spina bifida, behavior disorders, brain dysfunctions, mental retardation, cystic fibrosis, and muscular dystrophy, among others, who are unable to meet the eligibility requirements in spite of the fact that they are in and out of the hospital, depend on expensive medications and technological devices, and require expensive therapies to sustain their development and often their life.

These children had best be born into very wealthy families who have the resources to maintain the medical and developmental needs of their child or into a welfare family who is eligible for Medicaid based on impoverishment. The middle income family with an infant with multiple disabilities who is at risk of life-appropriate early intervention services, is placed in real jeopardy as they learn the extent of interventions necessary for their young child, the urgency for early therapies, and they weigh the costs against their income and their infant's ineligibility for SSI. As I am sure has or will be pointed out to you, the "equals" standard is very difficult to measure in a young child. We strongly urge you to put an end to this inhumane practice and adopt legislation such as H.R. 868 that will give children equitable treatment.

We also strongly endorse H.R. 71, Independent Living Trusts and Family Contributions Act, championed by Representative Steve Bartlett. Current SSI practices requiring that all contributions be considered income or assets available to the recipient creates extreme difficulty for families who are able or would like to assist their adult sons and daughters with clothing, food, and housing. Even minimal help results in a loss of SSI income. This practice thwarts family efforts to assist the government in providing even basic standard of living for persons who are aged, blind or who have disabilities. We urge speedy passage of this legislation.

In conclusion, on behalf of TASH, I wish to thank the Committee for holding this hearing and for listening to our comments on this hearing and for listening to our comments on this most important Federal program. We stand ready to assist the Committee and its members in any efforts to see the SSI program improved, or to provide information from our constituency in any area that will aid Congressional efforts to see a more equitable life for persons with disabilities.

Thank you.

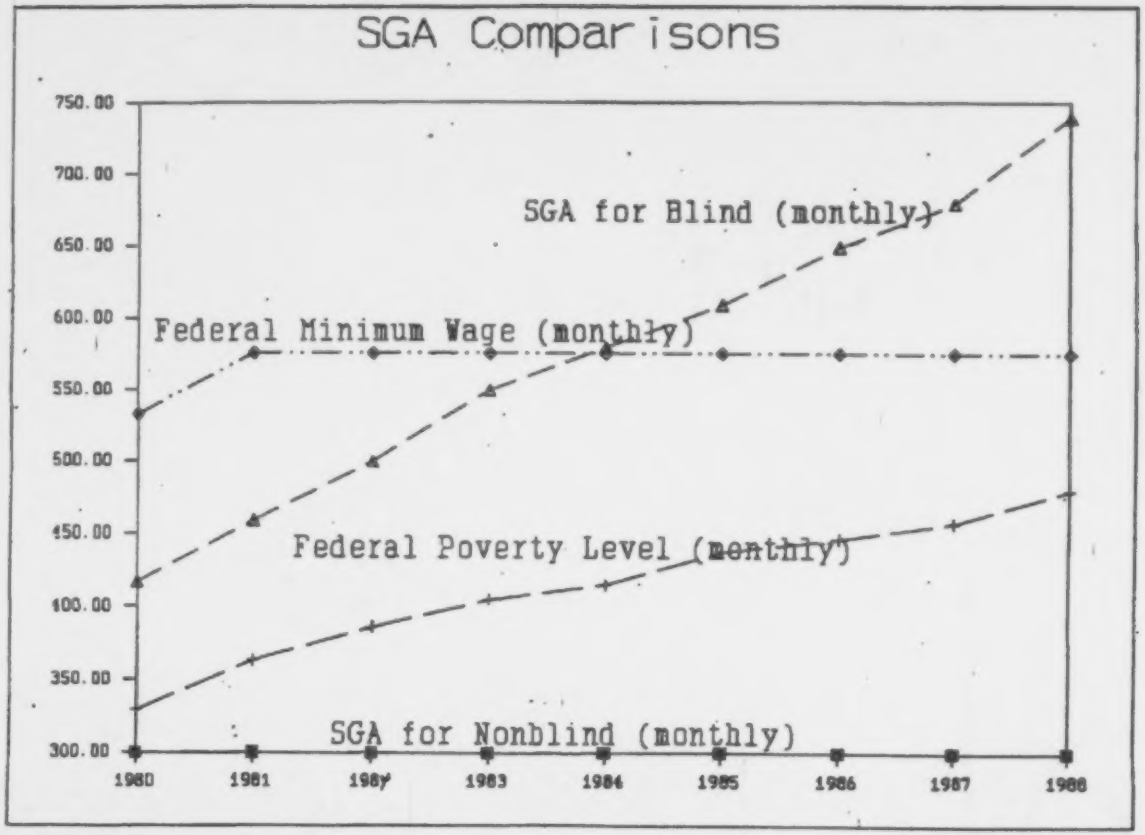

Figure 2 SGA Comparisons

A Study of Supplemental Security Income Awardees

by Charles G. Scott*

Since its enactment in 1974, the Supplemental Security Income (SSI) program has had a stable caseload of about 4 million recipients. Hidden by this unchanging total is the fact that nearly 9 million persons were served by the program from 1974 to 1986. This study explores some SSI program dynamics by following a group of SSI awardees for a period of 4 years from the initial receipt of award in 1981. Many of these awardees had previous contact with the program either through a previous award or a denial. About 60 percent of the awardees were eligible at the end of the 4-year period. Most persons who became ineligible did so within the first 6 months after the award.

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A Study of Supplemental Security Income Awardees
Charles G. Scott

Worldwide Trends and Developments in Social Security, 1985-87
Leif Haanes-Olsen

The 1989 Federal Poverty Income Guidelines

The Department of Health and Human Services published the "Annual Update of the Federal Poverty Guidelines" in the February 16, 1989, **Federal Register.**[1] As required by law, the 1989 update reflects last year's changes in the Consumer Price Index for All Urban Consumers (CPI-U). The Federal Poverty Income guidelines are a simplified version of the Federal Government's statistical poverty thresholds used by the Bureau of the Census to prepare its estimates of the number of persons and families in poverty. Both the thresholds and guidelines consist of a series of income levels, with different values for families of different sizes, below which the families are classified poor for statistical or administrative purposes.

The accompanying table shows that the 1989 poverty income guideline for an individual in 1 of the contiguous 48 States or the District of Columbia is $5,960—an increase of $210 from the previous year. In Alaska and Hawaii, the 1989 guidelines for the same size family are $7,460 (up $270) and $6,870 (up $220), respectively. As family size increases, in increments of one additional person per unit, the income level increases by increments of $2,040 in the contiguous States and the District of Columbia, by $2,550 in Alaska,

[1] See Federal Register, February 16, 1989, pages 7097-7098. For a more detailed description of the poverty income guidelines and definition, see Gordon M. Fisher, "The 1984 Federal Poverty Income Guidelines," Social Security Bulletin, July 1984, pages 24-27.

Federal poverty income guidelines, 1989[1]

Size of family unit	Contiguous States and District of Columbia	Alaska	Hawaii
1	$5,960	$7,460	$6,870
2	8,080	10,030	9,220
3	10,080	12,580	11,570
4	12,100	15,130	13,920
5	14,140	17,680	16,270
6	16,180	20,230	18,620
7	18,220	22,780	20,970
8	20,260	25,330	23,320

[1] For family units with more than 8 members, add the following amount for each additional family member: $2,040 in the 48 contiguous States and the District of Columbia, $2,550 in Alaska, and $2,350 in Hawaii.

The Supplemental Security Income (SSI) program is a cash assistance program designed to assure a minimum level of income to aged, blind, and disabled individuals whose income and resources are below specified amounts. Beginning in January 1974, SSI replaced the previous Federal-State adult assistance matching grant programs—Old-Age Assistance, Aid to the Blind, and Aid to the Permanently and Totally Disabled. Under the new SSI program, children could be found eligible on the basis of blindness or disability.

The current SSI caseload consists of recipients transferred from the previous State adult assistance programs in addition to new recipients awarded payments under the SSI program that began in 1974. In December 1986, there were 4,269,184 SSI recipients. The year-end caseloads for December 1974-December 1986 are shown in the tabulation that follows:

December	Caseload
1974[1]	3,996,084
1975	4,314,275
1976	4,236,999
1977	4,237,992
1978	4,216,925
1979	4,140,576
1980	4,142,017
1981	4,018,875
1982	3,937,590
1983	3,901,497
1984	4,029,239
1985	4,136,021
1986	4,269,184

These point-in-time caseload figures show a very small overall increase (less than 7 percent) since the end of the first year. These data portray SSI as a static social program and imply that a fixed group of individuals have been served since the establishment of the program. However, of the 4,269,184 recipients in December 1986, only 24 percent were transferred from the previous State programs. In this 13-year period, more than 6.9 million awards have been made in addition to the 3.2 million persons who were transferred from the former Federal-State assistance programs.

Even if it is assumed that some individuals have more than one award, it is evident that the program has served many millions more than the caseload data show. The following tabulation shows the number of awardees reported by the Social Security Administration (SSA), by year:

Year	Awardees
Total[1]	6,987,214
1974	880,788
1975	708,147
1976	648,868
1977	667,570
1978	632,447
1979	483,999
1980	496,137
1981[1]	389,061
1982[1]	306,069
1983	419,648
1984	554,251
1985[1]	886,748
1986	887,030

[1]Partly estimated; data were not available for some months.

This study was initiated to analyze some of the program dynamics resulting from the influx of new recipients. It follows the experience of a group of SSI awardees from before their awards through a 4-year postaward period.

Methodology

The study is based on a sample of 761 SSI awardees selected from the SSI 1-Percent Sample files for the period October-December 1981. The sample cases represent an estimated 76,100 awards during that 3-month period (see the Technical Note on page 12 for a discussion of the sample). Demographic and program data were extracted for these awardees from the following administrative data sources:

- SSI 1-Percent Sample: This file contains selected point-in-time information for current recipients, and is produced monthly from the Supplemental Security Record (SSR), the primary administrative file for the SSI program;
- SSR record displays: Where SSR data not contained in the SSI 1-Percent Sample file

were needed, hard copy displays of the SSR were obtained; and

- SSI recipient folders: Because some information collected by SSA is not needed for payment purposes, it is not placed on the SSR. The information on each recipient is contained in folders maintained by the agency. These folders were used for the study cases.

Preaward SSI Program Experience

Of the 76,100 payments awarded in October-December 1981, 22,800 were awarded on the basis of age and 53,300 were awarded on the basis of disability. In this study, an awardee was a person who received his/her first payment after filing an application. Although this process can often be straightforward, the road to an SSI award may have programmatic detours.

Program Experience Before Filing Application

Many of the awardees had applied for SSI payments before the application that resulted in their award. Of the 76,100 awardees in the study, 43 percent had previously applied for SSI payments and 17 percent had previously received an award. Further analysis shows that about 41 percent of the aged and 44 percent of the disabled had applied for SSI payments previously and 19 percent of the aged and 16 percent of the disabled had received awards (table 1).

The overall percentage of persons previously awarded SSI payments (17.3 percent) has some implications for SSA's awards statistics. The SSA records show that in 1974-86, 8.9 million persons were awarded SSI payments. Because some persons had more than one award, the actual number of different individuals served in the first 13 years of the program is probably closer to 5.7 million persons.[1] When these 5.7 million persons were added to the 3.2 million persons transferred from the former State assistance programs, a total of 8.9 million persons would have been served by the program from January 1974 through December 1986.

Table 1.—Number and percentage distribution of SSI awardees, by program category and previous program experience

Applicant status	Aged		Disabled[1]	
	Number	Percent	Number	Percent
All awards	22,800	100.0	53,300	100.0
No previous application	13,300	58.3	29,800	55.9
Previous application but no payment	5,150	22.4	14,700	27.6
Previous application and award[2]	4,400	19.3	8,800	16.5

[1] Because of small sample size, blind recipients are included in the disabled group.
[2] An applicant found ineligible (denied), who later meets the eligibility criteria, normally must reapply in order to receive SSI payments. A person who has received SSI payments and is no longer eligible generally must reapply if the period of ineligibility exceeds 12 months.

Period Between Application and Award

Typically an award is made within weeks after the application is filed. However, some awards result from reversals—through the appeals process—of previously denied applications. About 4 percent of the 22,800 awards to the aged and 24 percent of the 53,300 awards to the disabled were the results of appeal reversals (table 1). Because the appeals process can be lengthy and eligibility is protected from the date of the application, these awardees received retroactive payments for back months of eligibility. For awardees whose applications had not been denied, the retroactive period consisted of the time required to process the application. The average period of retroactivity was only 1.2 months for aged awardees and 4.0 months for disabled awardees who had no appeals. The averages were much higher among awardees who had gone through the appeals process (table 2).

Demographic and Program Characteristics at Time of Award

Sex

Nearly three-fourths of the aged awardees were women, as were only one-half of the disabled awardees (table 3). One reason for this is that women are somewhat less likely than men to have been employed a sufficient length of time to qualify for Social Security at a benefit level in excess of SSI. A second reason is that women have a longer life expectancy than men and thus many more of them live beyond age 65.

[1] The 8.7 million total may be an upper limit figure because a few recipients had more than two awards.

Table 2.—Number of SSI awardees and average months of retroactive payments, by program category

Awardees	Aged	Disabled
Total number	22,800	63,300
Months of retroactive payments for—		
All awardees	1.2	4.0
With appeal reversals	8.0	9.3
Without appeal reversals	1.1	2.4

Age

Although many of the aged recipients were awarded SSI payments on or near attaining age 65—the first year they qualified as aged—a large percentage of these individuals came onto the program rolls after age 69. Study data did not indicate the change in their situation that caused them to apply after age 69.

The age groups for the disabled show a bimodal pattern. The two largest age groups among awardees were those aged 18-29 and 50-64 (table 4). One reason for this pattern is the nature of the disabilities among these applicants, a subject that is discussed later. A possible reason for the increase in the number of disabled recipients after age 18 is the requirement that income and resources of parents be "deemed"[1] to their children under age 18 when the children live in the same household as their parents.

Household

Information was gathered on the type of dwelling in which the awardee resides, the number of individuals living with the awardee, and the relationship of these persons to the awardee.[2] The great majority of both the aged and the disabled awardees were living independently—that is, they were not in an institution (nor in any type of group arrangement (table 5)). Nearly one-half of the aged and more than one-half of the disabled lived in a house. A substantial percentage of the aged (34.2 percent) and disabled (24.8 percent) lived in an apartment. Smaller percentages of the awardees lived in rooms or mobile homes. Ten percent of the aged and 12 percent of the disabled lived in some type of institution.

Of those awardees living independently, the aged awardees lived with fewer persons than did the disabled. Among the aged awardees, 44.8 percent lived alone; of the disabled group only 18.6 percent lived alone (table 6). Only 7.4 percent of the aged lived with four persons or more, and 20.3 percent of the disabled lived with four persons or more.

A total of 21,500 persons were living in households with aged awardees and 102,200 persons were in households with disabled awardees (table 7). About one-fourth of the persons living with either the aged or disabled awardees were children—including sons and

[1] "Deeming" refers to the concept whereby the income and resources of person(s) responsible for the welfare of an eligible individual are considered in determining the eligibility and payment amount for an SSI recipient.

[2] Information on household situations was obtained from recipient folders. About 75 percent of these folders were available. Results shown here are based on information in the available folders. Counts in the tables have been inflated to match the study totals.

Table 3.—Number and percentage distribution of SSI awardees, by program category and sex

Awardees	Aged		Disabled	
	Number	Percent	Number	Percent
Total	22,800	100.0	63,300	100.0
Female	16,700	73.2	36,700	50.1
Male	6,100	26.8	26,600	49.9

Table 4.—Number and percentage distribution of SSI awardees, by program category and age group

Age group	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	22,800	100.0	63,300	100.0
Under age 18	...	...	7,100	11.3
18-29	...	...	12,900	20.4
30-39	...	...	6,700	10.7
40-49	...	...	7,900	13.7
50-64	...	...	20,700	32.8
65	6,300	28.5	...	...
66-69	6,200	27.2	...	...
70-79	6,800	29.9	...	...
80 or older	3,600	16.4	...	...

Table 5.—Number and percentage distribution of SSI awardees, by payment standard and program category

Payment standard	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees[1]	22,800	100.0	88,800	100.0
Independent living:				
House	10,800	46.0	52,000	62.5
Apartment	7,800	34.2	13,300	24.9
Mobile home or room	2,400	10.6	6,800	10.9
Institutionalized	2,100	9.3	6,300	11.8

[1]Only 76 percent of the recipients' letters were available. Percentages shown here are for those awardees and counts have been inflated to match study totals.

Table 6.—Number and percentage distribution of SSI awardees, by program category and number of persons in household

Payment standard	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	22,800	100.0	88,800	100.0
Not independent	2,100	9.2	6,800	11.8
Independent	20,700	90.8	47,000	88.2
Living with:				
None	10,800	44.8	8,900	18.8
1 person	5,800	22.8	10,700	20.1
2 persons	2,400	10.6	8,900	16.7
3 persons	1,800	8.8	6,700	12.6
4 persons	1,100	4.8	4,800	9.0
5 persons or more	800	2.8	6,000	11.8

Table 7.—Number and percentage distribution of SSI awardees, by program category and relationship to other persons in household

Cohabitant	Aged		Disabled	
	Number	Percent	Number	Percent
Total	21,800	100.0	102,800	100.0
Grandchild	8,700	39.4	8,700	2.6
Child	4,800	22.3	30,800	23.1
Spouse	4,400	20.3	6,800	9.8
In-law	2,400	11.2	2,300	2.3
Unrelated person	1,800	7.9	6,800	5.7
Aunt, uncle, niece, nephew	900	4.2	6,800	5.7
Sibling	1,100	5.1	23,800	23.2
Parent	100	.5	24,800	24.0
Grandparent	...	...	2,400	2.3
Other relative	800	2.8	400	.4

daughters of all ages. When children are excluded from the analysis of household composition, the situation of both the aged and disabled awardees changes considerably. Aged awardees tended to be living with grandchildren (28.4 percent) or a spouse (20.3 percent). Among the disabled awardees, parents (24.0 percent) and siblings (23.2 percent) were most likely to be sharing the household. Only a small percentage of unrelated persons were in households with either aged or disabled awardees.

Income

The amount of income is used to determine both eligibility for and the amount of a person's SSI payment. For SSI purposes, income is anything an individual receives during a calendar month that can be used to meet his or her needs for food, clothing, or shelter. Income may be cash or in kind. Among aged awardees, Social Security benefits were the major source of income other than their SSI checks. Nearly three-fourths of the aged group were receiving Social Security benefits at the time of the award. About 20 percent of the aged had no income other than their SSI checks. Social Security benefits were also the major source of income for disabled SSI awardees, although the percentage receiving them (20.5 percent) was much lower than for the aged (table 8). The majority of the disabled awardees had no income other than their SSI checks. A small percentage of the aged (6.8 percent) and of the disabled (6.8 percent) had earned income. Another small perpentage of each group had assistance based on need—mainly from the Aid to Families with Dependent Children (AFDC) program. Because eligibility

for SSI precludes receipt of AFDC, the records of these recipients had not been updated, by the award month, to reflect the discontinuance of AFDC payments.

Disability

A disabled awardee is one who meets the Social Security Disability Insurance program definition of disability: unable to engage in substantial gainful activity by reason of a medically determinable physical or mental impairment that can be expected to last for a continuous period of at least 12 months or to end in death. The most frequently cited diagnostic category was mental disorders.[4] This category includes psychotic conditions, neurotic disorders, and mental retardation. More than one-half of the awardees with mental disorders were mentally retarded (table 9).

About 40 percent of the disabled awardees in this study had a "developmental disability"—a mental or physical condition incurred before age 22 that may continue indefinitely. This term includes persons with mental retardation, cerebral palsy, autism, epilepsy, sensory impairments, congenital disabilities, or traumatic accidents. The age groupings of disabled awardees described above revealed a bimodal pattern. If developmental disability is arrayed by age, at least part of the reason for this bimodal distribution becomes clearer. The younger disabled awardees were more likely to be developmentally disabled than were the older awardees (table 10).

Although the small sample size does not permit an extensive analysis, many other differences exist between these two disability subgroups. Developmentally disabled persons are more likely to have a representative payee, are less likely to have Social Security benefits, and are less likely to have resources than are other SSI awardees. They are also less likely to leave the SSI rolls within 4 years of their awards.

[4]The administrative records used in this study contained the appropriate diagnosis for only 367 (66 percent) of the 556 disabled awardees. The percentages shown in table 9 are based on the diagnoses for these cases. Counts shown in tables 9 and 10 have been inflated to match the study totals. Diagnoses are based on the International Classification of Diseases, 9th Revision, Clinical Modification, 1979 (ICD-9-CM).

Table 9.—Number and percentage distribution of SSI awardees, by program category and source of income

Source of income	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	28,800	[1]100.0	63,200	[1]100.0
With no income	4,800	16.7	39,700	66.7
With income	19,300	80.2	28,900	44.3
Earned	1,600	5.6	3,000	6.6
Unearned income:				
Social Security	16,900	74.1	19,900	30.5
Assistance based on need	2,000	8.8	8,400	13.0
Other	2,600	11.4	5,900	11.1

Table 8.—Number and percentage distribution of SSI awardees, by disease classification

Disease classification	Number	Percent
All disabled awardees[1]	63,900	100.0
Endocrine, nutritional, metabolic	2,500	6.2
Mental disorders	21,200	40.0
Psychotic conditions	8,600	12.4
Neurotic disorders	3,300	6.2
Mental retardation	11,400	21.4
Nervous system and sense organs	7,100	13.3
Circulatory system	6,600	12.2
Respiratory system	2,500	4.7
Musculoskeletal and connective	5,100	9.6
Other	7,500	14.1

[1]Only 66 percent of the administrative records used contained the appropriate diagnosis. Percentages shown here are for these awardees and counts have been inflated to match study totals.

Payment Amounts

The amount of the federally administered SSI payment depends on a variety of factors including the availability of a State supplement. In 1981, 41 States and the District of Columbia provided a supplement to some categories of SSI recipients, and 16 of these States and the District of Columbia opted for Federal administration. The remaining 25 States administered the supplement themselves.[5] Tables 11, 12, and 13 show the distributions for Federal SSI

[5]State-administered supplements are not included in this study. These data are reported to SSA in summary form by the 27 States that administer their own supplements and cannot be analyzed on a case-by-case

Table 10.—Number and percentage distribution of SSI awardees, by age group and developmental disability status

Age	All disabled		Developmentally disabled		Nondevelopmentally disabled	
	Number	Percent	Number	Percent	Number	Percent
All awardees	83,300	100.0	31,000	100.0	52,300	100.0
Under 18	7,100	13.5	6,020	22.8	2,100	6.6
18-59	12,800	23.4	7,300	84.8	5,900	16.1
30-39	6,700	10.7	2,400	11.4	3,300	10.8
40-49	7,300	13.7	1,700	8.1	5,600	17.8
50-64	20,700	86.8	4,800	21.9	16,100	49.8

Table 11.—Number and percentage distribution of SSI awardees, by program category and amount of combined payments

Payment status and amount	Combined Federal-State payments			
	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	88,800	100.0	83,300	100.0
Not receiving Federal or State payments	800	2.2	5,800	6.8
Receiving either Federal or State payments	86,900	97.7	48,800	86.4
Less than $80	8,900	10.1	1,800	2.2
$80-$89	6,700	25.0	8,000	9.4
$90-$99	3,000	13.2	3,800	6.2
$100-$149	4,800	19.7	4,000	7.5
$150-$199	8,800	13.3	18,800	22.6
$200-$249	1,000	4.4	8,800	10.2
$250-$299	1,400	6.1	18,200	22.2
$300-$399	1,800	8.8	5,100	6.8
$400 or over	800	.9	2,800	4.3

Table 12.— Number and percentage distribution of SSI awardees, by program category and amount of Federal payment

Payment status and amount	Federal payment			
	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	88,800	100.0	83,300	100.0
Not receiving Federal payment	4,700	20.8	5,200	9.8
Receiving Federal payment	18,100	78.4	48,100	90.2
Less than $20	2,800	11.0	1,800	8.4
$20-$39	6,100	26.4	8,000	9.4
$40-$59	2,400	10.8	3,100	5.8
$60-$79	2,800	11.4	3,800	6.8
$80-$99	5,900	16.8	17,700	33.1
$100-$300	...	...	2,500	4.7
$301	1,900	8.3	14,800	27.8

payments, federally administered State supplementary payments, and a combination of the two. The amounts reflect payments projected for the month following the award month. The maximum monthly Federal SSI payment at the end of 1981 was $284. For those awardees in the study who were located in the 18 States (and the District of Columbia) offering a federally administered State supplement at that time, the supplement amounts ranged from $1 to $231 per month.

Aged awardees had lower combined SSI and State supplement payment amounts than disabled awardees. Nearly one-half of the aged awardees received combined Federal-State payments of less than $100, and fewer than one-fifth of the disabled awardees received payments of less than $100. The principal reason for this difference in percentages between aged and disabled awardees is the higher incomes of the aged awardees, primarily from Social Security benefits.

A few of the awardees were receiving neither a Federal nor State payment. These individuals were not scheduled to receive a payment beyond the award month because they were eligible for payments only on a retroactive basis—that is, their eligibility ended before SSA could make a payment. Despite their later loss of eligibility,

they did receive a payment for the specific period during which they were eligible.

Although a large majority of the awardees received a Federal payment, 13 percent did not receive Federal monies. Typically, this nonpayment occurs when income is high enough that the person is eligible only for a State supplement. Federal payments were much larger for disabled awardees than for the aged. Again, this difference reflects the higher incomes of aged awardees. About 27 percent of the disabled received the maximum Federal payment; only 8.3 percent of the aged received the maximum payment (table 9).

State supplementation payments were received by 45.2 percent of the aged awardees. Only 35.5 percent of the disabled awardees received such a payment. The size of the payments did not vary much between the two groups.

Alien Status

Another criterion of eligibility for SSI payments is that the recipient must be either a U.S. citizen or an alien lawfully admitted for permanent residence or otherwise permanently residing in the United States under "color of law." Persons are "lawfully admitted" if they follow the regular immigration procedures. Other persons may receive SSI payments if they are considered to be permanent residents under color of law. This group of individuals originally consisted of refugees who, for humanitarian reasons, were not required to follow the regular immigration procedures. This definition of permanent residents under color of law was broadened to include groups other than refugees.

Since October 1980, the income and resources of a lawfully admitted alien's sponsor have been considered in determining that alien's eligibility and payment amount. A sponsor is an individual who has signed an affidavit of support as a condition of the alien's admission for permanent residence in the United States. Consideration of a sponsor's income and resources is called "sponsor-to-alien deeming." This type of deeming can take place within a 3-year period from the time the alien is admitted to the United States for permanent residence or granted permanent residence status by the Immigration and Naturalization Service. Sponsor-to-alien deeming does not apply to aliens admitted under color of law.

About 18 percent of the aged awardees and 8 percent of the disabled awardees were lawfully admitted resident aliens. In the preceding section on income, it was stated that nearly 20 percent of the aged awardees had no income at the time of their SSI award. The majority of these aged awardees were lawfully admitted resident aliens, which explains, in part, why some aged awardees are not eligible for Social Security benefits—the most common form of income received by aged awardees.

Representative Payment

When it is evident that a recipient is not able to manage or direct the management of benefit payments in his/her own best interests, a person or organization may be selected to receive those payments on behalf of the recipient. Such representative payees are accountable for their use of benefits. Among the aged awardees, only 3 percent had representative payees, and 33 percent of the disabled awardees had a representative payee, typically a parent.

Table 13.—Number and percentage distribution of SSI awardees, by program category and amount of federally administered State supplemental payment

Payment status and amount	Federally administered State supplemental payment			
	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	22,900	100.0	83,300	100.0
Not receiving a State payment	12,600	54.8	94,400	94.6
Receiving a State payment	10,300	46.2	18,900	38.6
Less than $30	2,100	9.2	4,900	9.2
$30-$59	2,600	11.4	6,400	12.0
$60-$99	1,900	8.3	1,900	3.6
$100-$139	1,800	8.5	900	1.7
$140 or over	2,200	9.6	4,800	9.0

Four-Year Followup

This section discusses the varying lengths of time the awardees in the study remained in the SSI program and the reasons why some of them became ineligible for an SSI payment. These events were followed for the 4-year study period, beginning with the month of award.

In ongoing program operations, when a recipient becomes ineligible for an SSI payment, he/she may have payment(s) "suspended" for

up to 12 months—which means that during that year payments can be resumed without the need to file a new application. If a suspension continues beyond 12 months, eligibility is "terminated" and a new application is generally required before payments can begin. This article takes a longer range view and distinguishes between those who were in the program at the end of the 48-month study period (regardless of whether a suspension or termination occurred) and those who were ineligible at the end of the study period. For purposes of this study, the term closure (or closed case) is used to describe the cases of individuals who were not in payment status at the end of the 48-month study period, no matter what the reason for that nonpayment status.

Ineligible Awardees

During the study period, 30,900 of the 76,100 awardees (about 41 percent) became ineligible for an SSI payment (table 14). The time at which the case closure occurred shows a definite pattern. During the first 6 months following their awards, about 18 percent of the awardees became ineligible. After the first 6 months, the pattern shows greater variation, although the numbers never come near those for the initial period after the awards. This variation suggests that the SSI program serves as a short-term income source for many awardees. The ineligibility rates also differ between the aged and the disabled groups of awardees. The overall closure rate was about the same for the aged (36.2 percent) as it was for the disabled (41.7 percent). However, only one-third of the aged became ineligible during the first 6 months; in that same period, one-half of the disabled SSI awardees became ineligible for a payment.

The proportion of awardees who became ineligible during the study period varied by other characteristics. Case closures occurred most often among males and older awardees in either eligibility category (table 15). Awardees with other sources of income were more likely to become ineligible than were awardees with no other sources of income.

Reasons for Ineligibility

Excess income was the most often cited reason for an awardee to become ineligible for an SSI payment. Social Security benefits

Table 14.—Number and percentage distribution of SSI awardees, by program category and time elapsed after award

Eligibility status and elapsed time	Aged		Disabled	
	Number	Percent	Number	Percent
All awardees	52,800	100.0	53,300	100.0
Became eligible during study	14,100	61.8	31,100	58.3
Became ineligible during study	8,700	36.2	22,200	41.7
Months 1-6	2,900	12.0	11,000	20.6
Months 7-12	900	3.9	2,600	4.9
Months 13-18	1,200	5.3	1,900	3.5
Months 19-24	1,100	4.9	1,700	3.2
Months 25-30	900	1.9	1,400	2.6
Months 31-36	900	3.9	1,000	1.9
Months 37-42	700	3.1	1,700	3.2
Months 43-48	700	3.1	900	1.7

Table 15.—Number and percent of SSI awardees who became ineligible, by sex, age, and income status

Characteristic	Total	Number	Percent
All awardees	76,100	30,900	40.6
Sex			
Male	32,700	10,800	32.9
Female	43,400	14,400	33.2
Age			
Under 18 years	7,100	1,900	26.8
18-29	12,800	3,600	28.5
30-39	5,700	2,600	45.6
40-49	7,300	3,800	52.1
50-64	30,300	10,800	30.2
65	6,800	1,700	25.0
66-69	6,300	2,300	36.5
70-79	6,800	2,800	42.4
80 or older	9,800	2,008	67.1
Income status			
Other income source during period	64,800	25,100	48.0
No other income source during period	21,800	6,800	27.6

considerably more when an award is made to a younger person than when it is made to an older person (table 19). Costs to the State are not affected as much by the awardee's age, probably because the higher incomes of the aged (principally from Social Security benefits) are deducted first from the Federal portion of the SSI benefit.

Table 18.—Average payment amount during study period, by program category and source of funds

Source of funds	Aged	Disabled
Total	98,801	97,901
Federal funds	9,632	9,005
State funds	1,008	906

Table 19.—Average cost during study period, by age, sex, and source of funds

	Average cost	
Age and sex	Federal	State
Age		
Under 18 years	$8,998	$709
18-29	7,688	1,488
30-39	6,901	838
40-49	6,288	446
50-64	6,490	1,074
65	6,518	1,483
66-69	5,838	1,993
70-79	2,488	1,897
80 or older	2,748	1,038
Sex		
Male	$6,906	$993
Female	8,084	1,298

Conclusion

This study has provided a description of SSI awardees. Some of the most important facets of this description include:

- From January 1974 to December 1986, the SSI program served about 9 million persons.
- About 17 percent of the awardees in the study had been eligible for SSI payments before the study period.
- About 43 percent of the aged awardees did not receive their awards until they were aged 70 or older.
- The great majority of SSI awardees lived independently—that is, they were not institutionalized. Only about 10 percent of the aged and 12 percent of the disabled were institutionalized at the time of their award. Many of the aged SSI awardees lived alone (45 percent). Only 19 percent of the disabled awardees lived alone.
- More than 80 percent of the aged awardees had some form income at the time of award. Typically, this income was in the form of Social Security benefits. Of the 20 percent of the aged awardees who had no income, the majority were aliens. Only 44 percent of the disabled SSI awardees had any income at the time of award.
- Among the disabled awardees, 40 percent had a developmental disability.
- The majority of the awardees in this study (59 percent) were receiving payments at the end of the study period. Of those who were ineligible for payments at the end of the 48-month period, nearly one-half had become ineligible during the first 6 months following their award. Many of these individuals, particularly in the disabled group, became ineligible because they began to receive Social Security benefits, indicating that SSI serves in a temporary income-support role for some persons while they are waiting for their Social Security disability insurance benefits to begin.

Technical Note

The cases in this study were identified from the SSI 1-Percent Sample file, a file that is extracted each month from the Supplemental Security Record (SSR)—the main computer file used in administering the SSI program. Certain digits of the Social Security number of each recipient were used to achieve a random sample of SSI awardees for the last 3 months of 1981. Although the awardees selected in this manner are representative of all SSI awardees in late 1981, they may not be representative of awardees before or after that time period.

Estimates based on the SSI 1-Percent Sample may differ from the figures that would have been obtained had all, rather than a sample, of the records been used. These differences are termed sampling variability. The standard error is a measure of sampling variability—that is, the variation that occurs by chance because a sample is used. The standard error is used to describe confidence intervals. The confidence interval represents the extent to which the sample results can be relied on to describe the results that would

occur if the entire population (universe) rather than the sample had been used for data compilation.

In about 68 percent of all possible probability samples with the same selection criteria, the universe value would be included in the interval from one standard error below to one standard error above the sample estimate. Similarly, about 95 percent of all possible samples will produce estimates within two standard errors, and about 99 percent will produce estimates within two-and-one-half standard errors.

Tables I and II provide approximations of standard errors of the estimates shown in this article. Table I presents approximate standard errors for the estimated number of recipients from the 1-Percent Sample file. Table II presents approximations of standard errors for the estimated percentage of persons from the 1-percent file. Linear interpolation may be used to obtain values not specifically shown.

The reliability of an estimated percentage depends on both the size of the percentage and the size of the number on which the percentage is based. The standard errors are expressed as percentage points and the bases are shown as inflated to the actual size of the universe from which the sample was drawn. To illustrate: The study data show that 58.3 percent of the 22,800 aged awardees filed no previous application for an SSI payment. For a base of 10,000, table II shows a standard error of 5.3 percent for an estimate of 50 percent. For a base of 50,000, the standard error for the same estimate is 2.4 percent. Because the figures in table II do not cover the exact estimates that are being evaluated, it is necessary to interpolate between the values shown in that table. This interpolation results in a standard error of 5.1 percent. The limits for a 95-percent confidence interval (two standard errors) are therefore 58.3 percent plus or minus 10.2 percent, or 68.5 and 48.1, respectively. Thus, the procedure for defining 95-percent confidence intervals as the estimate plus or minus two standard errors—in this case, 58.3 percent plus or minus 5.1 percent—produces intervals having a 95-percent chance of containing the actual percentage of aged awardees who had not filed previous applications.

Table I.—Approximations of standard errors of estimated numbers of persons from a 1-percent file

Size of estimate (inflated)	Standard error
500	200
1,000	300
2,500	500
5,000	600
7,500	900
10,000	1,100
25,000	1,700
50,000	2,400
75,000	3,000
100,000	3,400

Table II.—Approximations of standard errors of estimated percentages of persons from a 1-percent file

Size of base (inflated)	Estimated percentage				
	2 or 98	5 or 95	10 or 90	20 or 75	50
1,000	4.7	7.3	10.1	14.6	16.6
10,000	1.5	2.3	3.2	4.6	5.3
50,000	.7	1.0	1.4	2.1	2.4
100,000	.5	.7	1.0	1.5	1.7

Mr. STEIN. May I make one small addition. There was a question from Mr. Ford to Mr. Enoff about the Fox report and we think that Mr. Enoff's response was a lame response in terms of the reference to telephone methodology. In fact, there was a variety of sources well beyond telephone interviews used by the researchers, and we have good reason to believe that that report is not out before this committee and before the public because it simply comes to some conclusions about the inadequacies of this program, which at least some people in the Social Security Administration just don't want out there.

We would urge the committee to ask the Secretary to release the report. If they have questions about methodology. they can certainly release the report with some appendage that lays out Mr. Enoff's or Ms. Hardy's questions that she may have. There is absolutely no reason—this report was completed months ago, and it is one of the—it is a fairly well read document because there is little study, particularly government funded studies about the inadequacies of the SSI program, and we feel there is a strong interest in having that made public now.

Acting Chairman DOWNEY. Mr. Stein, you have worked on the *Zebley* case and you argued, I think, that it was the intent of Congress to provide functional assessment of children analogous to the assessments of residual functional capacity provided to adults. You are not suggesting we wait for the Supreme Court decision?

Mr. STEIN. No, we urge prompt congressional action now.

Acting Chairman DOWNEY. Dr. Katcher, you testified children should receive functional assessments, presumably from pediatricians and that it would be similar to that received by adults. The administration seems to think this is unnecessary for children. How would you perform a functional assessment of the child and why do you think the administration thinks this is unnecessary?

Dr. KATCHER. I don't know why the administration thinks or acts as it does, and I don't feel competent to comment on that. As to how pediatricians should perform functional assessments, some children could be assessed by a single pediatrician, and some children would require a multidisciplinary assessment involving many professionals.

There are institutions, academic and community, throughout the United States which are qualified to perform assessments. The purpose of an assessment is to determine, first of all, what is the state of health and what are the related health impairments. In other words, the assessment determines difficulties or problems and strengths of the medical nature of the child.

Second, an assessment determines the nature of the medical diagnoses which have led to those impairments.

Third, an assessment determines the coping abilities and the advantages which a child possesses, as well as the disadvantages.

Fourth, as assessment determines the coping abilities which the family and community bring to support that child, as well as determine the problems inherent in whatever the family structure or home situation or community environment might be.

That is what I would call a comprehensive functional assessment.

Acting Chairman DOWNEY. Thank you.

Ms. Mulligan, the problem is really the question of Medicaid eligibility. If we could find a way to work through the Medicaid program to make her eligible that would solve the problem, would it not?

Mrs. MULLIGAN. No, Mr. Chairman. I think the problem at hand at this time is clearly Social Security supplemental income that my daughter was receiving, and I think that it is something that you should know, that whether it be $98 or $200 or $342 per month, that money is clearly necessary both for this family and for many more like ourselves. That money could be used to help buy things that are not covered by Medicaid that we cannot afford to pay for all on our own with only one person's income.

We never seem to go over the fact when we speak about all—today we speak about the fact it takes two incomes to make ends meet and that is what we call normal children to take care of.

Acting Chairman DOWNEY. Sure.

Mrs. MULLIGAN. I now am not working and the reason why I am not working is because I am taking care of my daughter, and I think that any mother that is accustomed to working could tell you also how hard it is for you not to work when you really, really need to. And I think that the idea that my husband has been cut off from his ability to work any overtime, to say that he could work—if my daughter was to receive SSI and Medicaid on the Federal level, my husband would not be able to work any overtime, he would not be able to get anything extra. And that is how the system stops these people from working.

Now, if my husband were to leave our home, then my daughter would be taken care of, my two sons would be taken care of, and I would be taken care of, and that is a cost that is three times more than what the taxpayers originally would have incurred. So I think it is promoting people to say I am sorry, I don't live here at the home any more and my wife will have to collect welfare and have medical insurance for the sick child and the other children.

Acting Chairman DOWNEY. It is a perverse set of options that go with it. Clearly you are not better off if your husband leaves home, even if you were eligible for Medicaid or a result.

Mrs. MULLIGAN. Any time I have been in Washington—and I hate to say this—but we always have to talk about the money. That is pretty hard to put a price tag on any child's head and I don't think anybody here as a parent likes to do that, and that is the way it is when you have a handicapped child.

Acting Chairman DOWNEY. Apparently Secretary Bowen was unafraid to tell you that.

Mrs. MULLIGAN. He was very cold, Mr. Chairman, and I have to tell you that Louis Enoff was also in that meeting, as well as three or four other people, and I felt that the system purports to promote family unity, and if that meeting was an example of their supporting family unity, then I can clearly see why people do things unjustly.

Acting Chairman DOWNEY. Didn't you have a chance to present things to then candidate Bush in your State, in New Hampshire?

Mrs. MULLIGAN. Yes, I did.

Acting Chairman DOWNEY. What did he say to you?

Mrs. MULLIGAN. Then Vice President Bush called me to—first he called to apologize for a comment that he made, which I accepted his apology, Mr. Chairman. I felt it was genuine and I did not want to pursue the issue, but at the same time, I took the opportunity to let him know what was going on with the Social Security rules and regulations, how they are 25 years outdated and arcane, and at that time, he agreed with me. He said he would do everything in his power to make the wrongs right.

Then again in August, after I had taken Kaileigh to a visual type situation in New Hampshire, he called me and he called to tell me that he had developed and devised a new Federal waiver program on behalf of the issue that I had raised, which would affect every State in the country. That press release and that announcement consisted of a Federal waiver program that would provide nonprescription drugs and diapers.

Well, I can only tell you I have yet to see one diaper or any nonprescription drugs that have helped this family, and I think that everybody knows we have a handicapped child here. Your nonprescription drugstore bill could be anywhere from $100 to $200, which I documented for then Vice President Bush as well as Health and Human Services. So I am very disappointed. I asked for a whole different change in the Social Security rules and regulations, which the rule does say that Secretary Bowen can make a case by case decision, he chose not to, and I did not get the result that I thought that I would from then Vice President Bush.

My hope is that within his words of the kinder and gentler nation, I cannot think of any better place to start than with these children who suffer with great pain and have great disabilities. I think that the money that we need for the availability for these children could certainly be stretched to help these families.

Acting Chairman DOWNEY. Well, Mrs. Mulligan, and Mr. Reese, you made very powerful statements to this subcommittee. We are going to do what we can as well to try to correct this.

I don't want to sound like all those dispassionate bureaucrats you may have heard before. We have to convince 281 of our colleagues in the House of Representatives and 51 Members of the Senate, and then get a Presidential signature.

Mrs. MULLIGAN. I would like to just say one more thing, Mr. Chairman.

Acting Chairman DOWNEY. Go ahead.

Mrs. MULLIGAN. I can tell you that when you talk about the bureaucrats, my very first experience was very cold I was told by Secretary Bowen's office that they do not speak to the public, I have to really commend you for taking this opportunity to speak to us as parents, and you have done a nice job.

Acting Chairman DOWNEY. Thank you.

We speak to the public often and you would be surprised how often they speak to us.

Mrs. MULLIGAN. I think Secretary Otis Bowen was working too hard at having his secretaries screen his calls.

Acting Chairman DOWNEY. We have a different Secretary.

I want to thank the members of the panel. You have been very helpful.

Acting Chairman DOWNEY. Next, we have a panel with Save Our Security Coalition, the Honorable Arthur Flemming, who is the chair, and we are especially honored to have Mr. Flemming. He was a former Secretary of the Department of Health, Education and Welfare. I suspect if Mrs. Mulligan had had a chance to see him, the outcome would have been a little different.

Acting Chairman DOWNEY. Mr. Secretary, we will receive your testimony first.

STATEMENT OF HON. ARTHUR S. FLEMMING, CHAIR, SAVE OUR SECURITY COALITION, FORMER SECRETARY OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Mr. FLEMMING. Thank you.

First of all, thank you for holding this hearing. SOS is a coalition of over a hundred organizations committed to protecting and improving the health and income security programs which our Government provides. There are five major points I would like to underline today:

First, the current SSI Federal benefit levels are way too low. SOS supports the language in both H.R. 866 and H.R. 361 to raise the benefits to the poverty level.

Second, we urge you to act immediately to pass the provision in H.R. 866 which mandates that the SSA provide outreach assistance.

Third, SOS supports the provisions of H.R. 866 to clarify the standard for adjudicating children's disability claims and to make more reasonable the asset limitations.

We recognize, despite the language in the present statute, which requires the Secretary to provide SSI to children whose impairments of comparable severity to workers. SSA has failed to take into consideration the functional limitations of a child's impairment and has failed to consider the combined effects of a child's impairments in assessing whether the child is disabled.

We also recognize that the Circuit Court of Appeals has told SSA its position violates the statute. However, as has been noted, that is being appealed to the Supreme Court. Therefore, we feel that the prompt action by the Congress to clarify this issue would dramatically improve the present situation for several disabled children.

Fourth, many of the provisions in H.R. 867, while technical and inexpensive, will make a significant difference to those individuals affected by the current arbitrary rules.

Fifth, SOS supports the thrust of H.R. 8, which is designed to improve the work incentives which are available to people who receive Social Security disability benefits.

We feel that the package which is currently being considered, we recognize that it is a modified version of the original H.R. 8, but we do feel even the modified version will represent a substantial correction in the right direction.

The 1972 law bringing the supplemental security income program into existence was landmark legislation. The landmark legislation has not led, however, to landmark results. The income floor is indefensible. In 1989, the maximum Federal benefit amounts to $85 for an elderly person living alone are about 75 percent of the

Federal poverty guidelines. The Social Security Administration's totally inadequate outreach program has resulted in a situation where only one half of holder persons are eligible for SSI are actually paid it.

Mr. Chairman, I am sure that you and your colleagues and the staff have had their attention called to a report put out by the Builders Foundation entitled "Is SSI Aware Why the Elderly Poor Don't Get the Help They Were Promised". It is a survey of 6,200 older Americans conducted by the foundation by 18 senior citizen groups in 15 States. And that report clearly demonstrates that the Social Security's own program has been totally inadequate.

There is no doubt in my mind but that it is imperative for the Congress to mandate action in this area; to mandate the development and implementation of an action program. You hear talk about lack of staff. We have been before the Social Security Subcommittee and this committee a good many times calling attention to the fact that over the last few years the administration refused to recruit the number of staff persons that the Congress appropriates money for. That just doesn't make sense.

Over on the Senate side, they got frustrated enough they put in a requirement for a floor. Now, that didn't fly too well over here in the House so far, but it seems to me that some action of that kind may be required if that kind of a policy continues to be implemented.

There are the staff resources available to implement an honest to goodness action program designed to reach these 2 million persons who are eligible and who desperately need what SSI could provide.

Personally, I believe, and I feel the organizations that I represent believe that a renewed nationwide commitment must be made to bring the SSI floor up to the poverty line and defined, in form and effectively assist those older disabled and blind persons who urgently need but have not received the SSI benefits to which they are entitled.

A failure to renew our national commitment in this way will once again lend credence to the feeling that we are a nation that when confronted with human needs, is long on promises and short on the actions required to redeem those promises.

Thank you very much.

[The statement follows:]

STATEMENT OF ARTHUR S. FLEMMING, SAVE OUR SECURITY COALITION

I. Introduction

A. I appreciate this opportunity to testify on the very important issues facing this Subcommittee relative to the Supplemental Security Income program.

B. The Save Our Security Coalition is a coalition of over one hundred organizations committed to protecting and improving the health and income security programs which our government provides.

C. There are five major points I would like to address today.

II. Body

A. First, the current SSI federal benefit levels are too low.

1. It is impossible for the aged, blind or disabled to maintain a defensible standard of living on the present monthly benefit.

2. SOS supports the language in both H.R. 866 and H.R. 361 to raise benefits to the poverty line.

B. Second, we urge you to act immediately to pass the provision in H.R. 866 which mandates that SSA provide outreach assistance.

1. Positive action is essential on the part of the Federal Government to reach the 1.5 to 2 million persons who are eligible for SSI but who have not yet established their eligibility.

2. One feature of the outreach language requires SSA to notify all low-income Social Security beneficiaries on an annual basis that they may be eligible for SSI.

3. Establishing eligibility for SSI will not only provide the beneficiary with additional income but in most states will also make the beneficiary automatically eligible for Medicaid.

C. Third, SOS supports the provisions of H.R. 868 which are designed to clarify the SSI standard for adjudicating children's disability claims and to make more reasonable the assets limitations.

1. Both steps would eliminate many of the administrative decisions which are currently being made to deny children who are both poor and severely disabled the SSI and Medicaid benefits they desperately need.

2. Despite the language in the present statute which requires that the Secretary provide SSI to children whose impairments are of comparable severity to workers, SSA has failed to take into consideration the functional limitations of a child's impairments and has failed to consider the combined effects of a child's impairments in assessing whether the child is disabled.

3. The Third Circuit Court of Appeals has now told SSA that its position violates the statute. Zebley v. Bowen, 855F.2d67 (3d Cir. 1988). However, the Secretary and the Solicitor have asked the Supreme Court to review that decision.

4. Prompt action by the Congress to clarify this issue would dramatically improve the present situation for severely disabled children.

D. Fourth, many of the provisions in H.R. 867, while technical and inexpensive, will make a significant difference to those individuals affected by the current arbitrary rules.

1. We urge you to include as many of these provisions as possible in the Subcommittee's budget package.

2. For example, the provision which will reduce the time when a couple who separates will continue to be treated as a couple will help those SSI recipients, mostly women, who flee domestic violence or the threat of it, by assuring that they have the full SSI benefit immediately. The cost is minimal, but the impact significant.

3. While inclusion of these provisions in a package will not address the need to raise the benefit level, it will eliminate some of the provisions which currently act as barriers to eligibility for individuals who are both poor and aged, blind or disabled.

E. Fifth, SOS supports the thrust of H.R. 8 which is designed to improve the work incentives which are available to people who receive Social Security disability benefits.

1. The package currently being considered is a modified version of H.R. 8. It contemplates:

(a) a program like the SSI work incentive program for those Social Security beneficiaries who receive disabled adult children's benefits;

(b) enabling individuals receiving disability benefits to buy-in to the Medicare program while they are working once their Medicare benefits have expired;

(c) providing, on a sliding scale, full or partial subsidy by the state Medicaid program of the costs of the premiums for those who buy-in who have incomes less than 300% of poverty; and

(d) providing an option for Social Security disability beneficiaries to shift to the SSI work incentive program when they have exhausted all of their Social Security benefits, provided the SSI income and resources rules are met.

2. The provisions in this very important package do not all fall under the jurisdiction of any one (or even two) subcommittees.

3. We urge this Subcommittee to work with the Social Security and Health Subcommittee as well as the Subcommittee on Health in Energy and Commerce to make this package a reality in this session.

4. The ability to work and provide for one's self, even if one is able to only partially meet one's needs, is critical for all of us, young and old, able and disabled.

5. This package will provide the opportunity to work which many who are disabled desire. The benefits to these individuals and to our country and its economy are immeasurable.

6. We hope that you will take the steps necessary to orchestrate passage of this very important package as part of the budget legislation.

III. Conclusion

A. The 1972 law bringing the Supplemental Security Income program into existence was landmark legislation.

1. It established the principle of an income floor for the aged, blind and disabled.

2. It placed responsibility for the implementation of the law on an agency that had the grassroot capacity to conduct an outreach program that would acquaint the aged, blind and disabled with the information they need relative to the benefits and eligibility requirements incorporated in the SSI law.

B. Landmark legislation has not led to landmark results.

1. The income floor is indefensible—in 1989 the maximum federal benefit amounts to $85 a week for an elderly person living alone, or about 75 percent of the federal poverty guidelines.

2. The Social Security Administration's totally inadequate outreach program has resulted in a situation where only one-half of older persons eligible for SSI actually participate.

C. A renewed nationwide commitment must be made —

— to bring the SSI floor up to the poverty line; and

— to find, inform and effectively assist those older, disabled and blind persons who urgently need—but have not received—the SSI benefits to which they are entitled.

D. A failure to renew our national commitment in this way will once again lend credence to the feeling that we are a nation that, when confronted with human needs, is long on promises and short on the actions required to redeem those promises.

Acting Chairman DOWNEY. Thank you. Ms. Sweeney.

STATEMENT OF EILEEN P. SWEENEY, STAFF ATTORNEY, NATIONAL SENIOR CITIZENS LAW CENTER

Ms. SWEENEY. Thank you. I would like to thank you and the members of the subcommittee for all your efforts on behalf of SSI recipients and those who should be on SSI but are not.

I agree with the other witnesses that the requiring outreach, clarifying the rules for disabled children, and eliminating or modifying the one-third reduction level, are critical. I would like to make three other points:

First, there are quite a few provisions in H.R. 867, H.R. 868 and H.R. 866 which have no or minimal costs, and they are discussed in my written statement. The net results of including those types of provisions is to eliminate some of the clutter and barriers currently in the program. It would be helpful if you would include as many of those as you can in your package. They make for a simpler, fairer program, and given their minimal cost, I don't think they should cause too much anxiety for anybody.

The second thing is Mr. Bartlett's testimony. It is very exciting that there is something that can be done for Social Security disability recipients. This subcommittee has taken the lead in the past on work incentive issues in section 1619 (a) and (b), and it is really remarkable, I think, it has taken so long on Social Security, but now we are in a position where something can be done for people and it would be tremendous if this subcommittee could do the portion that would allow Social Security beneficiaries, when they have exhausted all their other Social Security benefits, to move into the SSI program if they are otherwise eligible.

My last point has to do with the provision that seems to get lost in the shuffle; that is something called the $6,000/6-percent rule. This is a provision that affects mostly SSI children, those who could be SSI disabled children, and some disabled spouses. They tend to be poor farm families and what happens is SSI looks at a resource that generates income and puts a $6,000 cap on it. If you are a farmer, and have a farm where your land is excluded but you have some cattle on it or machinery, getting under the rule is virtually impossible.

What ends up happening, is they have to choose between the disabled kid and their farm. Is the farm going to continue? Or will the child get benefits? Two courts have said SSA's rules are arbitrary. They were set back in the seventies. In 1985 when SSA put them in the regulations, I asked for a copy of their study. They said "we destroyed it because it was obsolete. It was so old."

That was their actual reply in a letter to me. The food stamp program already does what the provision in H.R. 868 covers which says you look at the income, not the value of the resource. I think that it would be helpful if that could be done in the SSI program as well.

Two courts have said the current rule is arbitrary and capricious. If this subcommittee enacts the clarifications in the disability standards in place now, if the child is unfortunate enough to have a farmer as a parent, he still won't get on the SSI program.

Thank you.
Acting Chairman DOWNEY. Thank you.
[The prepared statement follows:]

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TESTIMONY OF EILEEN P. SWEENEY, STAFF ATTORNEY, NATIONAL SENIOR CITIZENS LAW CENTER, BEFORE THE HUMAN RESOURCES SUBCOMMITTEE OF THE WAYS AND MEANS COMMITTEE MAY 30, 1989

My name is Eileen Sweeney. I am a staff attorney at the National Senior Citizens Law Center, specializing in the SSI and Social Security problems facing low-income elderly and disabled people.[1]

There are five very fine SSI bills which have been introduced, H.R. 866, 867, 868, 360 and 361. My purpose here is to discuss some of the issues which these bills address which are not likely to be the main focus of the witnesses who testify at this hearing. As a result, I do not address the critical need for improvements in the SSI benefit level, the assets test, or outreach.

The need for major improvements in this program are all too apparent. While the other provisions in the three bills, H.R. 866, 867, and 868 are more modest in their scope, they essentially have the same goal: assuring that aged, blind and disabled individuals have the income and health care coverage they need. For example, if you are one of the persons to whom the $6,000/6% rule is applied, it does not matter that it is a relatively insignificant provision in the big picture, the result is as devastating to the individual as if there was no SSI program at all.

Below is a discussion of the need for the provisions included in H.R. 866, 867, and 868. I also discuss the need for a sound work incentive program for Social Security disability beneficiaries and the advantages of passing a revised version of H.R. 71.

Sections 102 and 103, H.R. 866: limiting the one-third reduction and providing for Medicaid eligibility in cases where the one-third reduction applies and the result is ineligibility for SSI

In her testimony before the Select Committee on Aging in September, 1988, Peggy Smith, testifying on behalf of Carmen Lacayo, President/Executive Director of Asociacion Nacional Pro Personas Mayores, stated:

> "Other actions, too, are needed to perfect and improve S.S.I. One of the most important is to repeal the existing measure that reduces that Federal S.S.I. benefit standard by one-third when elderly recipients reside in the house of another and receive maintenance and support. That provision discourages families from helping older relatives, and it causes some aged Hispanics to be prematurely or unnecessarily institutionalized."

1. Portions of this statement are identical to the written statement which I submitted for the record at the joint hearing held on March 2, 1989 by this Subcommittee and the House Aging Committee.

"The Elimination of Poverty Among the Elderly: Supplemental Security Income Reform," Hearing before the Subcommittee on Retirement Income and Employment, Select Committee on Aging, Comm. Pub. No. 100-700, page 30 (September 16, 1988).

There could not be a clearer statement of the serious problems created by the one-third reduction. Sections 102 and 103 of H.R. 868 will ameliorate some of the effects of the current rule. First, Section 102 permits a person to establish that the amount of the in-kind contribution which s/he receives is actually less in value than one-third of the benefit and that therefore SSA should reduce the benefit by a lesser amount. While this will not eliminate the one-third reduction, it will at least permit those elderly persons who reside with very low-income relatives to prove that the contributions from others in the household are less than one-third of the SSI benefit. In the very poorest households, this will result in less of the SSI benefit being withheld.

Second, there are people who do not receive SSI because of the one-third reduction. This is because they have some other source of a small income, usually Social Security or veterans' benefits. The result is that when they live in the household of another and receive support and maintenance from those in the household, this in-kind income (deemed to be equal to one-third of the benefit) when added to the other income renders the person ineligible for SSI. In many states, the result is that the person also does not receive Medicaid. Section 103 provides that even though the person will not be eligible for a cash benefit, the person will be considered to be an SSI recipient so that s/he will be eligible for Medicaid. This should help in preventing some of the problems cited by Ms. Lacayo: with Medicaid coverage in the community, it may be possible to avoid premature and/or unnecessary institutionalization for many of the nation's elderly poor.

While it would obviously be far more desirable to simply eliminate the one-third reduction entirely, these two provisions represent improvements which will dramatically limit the impact of the current provision for at least some of the elderly poor.

<u>Section 101 of H.R. 867: Treatment of workers' compensation and unemployment compensation as earned income for SSI purposes</u>

Currently, unemployment compensation and worker's compensation benefits which are received by an SSI recipient or the SSI recipient's spouse or, in the case of a disabled child, the SSI recipient's parent, are treated as unearned income. This means that only $20.00 of the income is disregarded. This creates very serious problems where the person, usually the spouse or parent, has been working and loses his/her job and begins to receive one of these benefits. The person's earnings were treated as earned income. This means that the person was permitted to disregard $85 plus 1/2 of the remainder from consideration for SSI purposes. As a result, when the person loses the salary but begins to receive the benefit, the purpose of which is at least partial salary replacement, the SSI recipient's eligibility is jeopardized.

Despite the fact that there is a drop in the family's income when the person loses his/her job and becomes eligible for the benefit, the difference in treatment means that the family will be treated as if they have more income for SSI purposes than when the person was working and earning far more. The provision in the bill changes this by requiring that these benefits be treated as earned income.

This will assist the family in smoothing the transition from earnings to benefits and will protect the SSI recipient from loss of critically needed benefits at a time when the family is even less able to meet the person's needs than when the family member was working.

Proposed addition to the legislation: Another problem along these lines has recently been called to my attention. In cases where the parent of a disabled child is also disabled and receiving Social Security disability benefits, SSA allows the parent to keep the equivalent of the federal SSI benefit rate before deeming the rest to be available to the SSI child. SSA ignores the fact that many states also provide state supplementation. If the disabled parent had been receiving SSI instead of Social Security, SSA would not have counted either the federal SSI payment or the state supplementation. The result is that the disabled parent who receives Social Security is allocated less to live on than an SSI disabled parent. It would be very helpful if there was a provision in the statute which clarified that SSA should disregard not only the federal SSI level but also any state supplementation in determining how much of the income of the disabled parent on Social Security will be deemed to the disabled child who is applying for SSI.

Section 102 of H.R. 867: Eligibility determinations for certain months in the cases of individuals with weekly or biweekly income.

In some families where one person receives SSI, there is a worker whose income is deemed to the SSI recipient and who is paid by his or her employer on a weekly or biweekly basis. The payment formula places the SSI recipient's benefits in jeopardy every time that there is a month that has an extra pay day in it, usually when there is a fifth Friday in the month. In those months, the worker who is paid weekly receives a fifth paycheck and the person paid biweekly receives a third. To avoid the current situation where the SSI recipient loses eligibility for one month and then returns to the program the next month, this provision would require SSA to average the worker's income so that there would not be the one month in which eligibility would be lost. This eliminates an unintended result of the placement of Fridays in the calendar and will bring some security and rationality in the SSI program to those families who have this problem.

Section 103 of H.R. 867: disregard of certain in-kind gifts

Every year when SSA is redetermining the eligibility of SSI recipients, the SSA worker asks the recipient whether they have received any income or gifts from family or friends or if they have seen their children or other family members. Invariably, some SSI recipients proudly tell of the plane, bus or train ticket which their sons, daughters, brothers or sisters sent so that the elderly or disabled SSI recipient could come to visit for the holidays. Because SSA treats this ticket as income, the SSA worker determines that, in one month, the SSI recipient was overpaid and owes SSA all or part of the SSI benefit for that month.

Apparently in an effort to mitigate some of the damage of this absurd rule, SSA has stated, in Social Security Ruling 80-22, that it will not count the ticket as income if it could not have been converted to cash by the SSI recipient. This would be the case where the recipient's relative charged the ticket to his/her credit card. If the recipient attempted to cash in the ticket, the credit would be made to the relative's account; cash would not be provided to the recipient. Under this circumstance, SSA does not count the value of the ticket as income. So, if the relative is well enough off to have a credit card, the SSI

recipient is fine, but this is not so in cases where the SSI recipient's relative does not have a credit card and must pay cash.

Section 103 solves this problem in the only fair, administratively simple, fashion: these tickets would no longer be treated as income. This recognizes that the ticket was given for purposes of travel, not to subsidize food, shelter, or clothing, and that it is simply a fiction to expect that it was used any differently. This is not a costly provision. Yet, it will be very helpful in eliminating the "hassle" factor for SSI recipients and, for those who get caught in the lair of the current rule, it will mean that they will have their entire benefit when they need it.

Section 104 of H.R. 867: Reduction in time during which the income and resources of separated couples must be treated as jointly available.

As the statute is currently written, when a married couple who receive SSI separates, SSA treats them as if they are still together and sharing their income for six months after the separation. This fiction creates incredible hardship for the member of the couple, usually the wife, who has the least income. Typically, the husband will have some other source of income as well, such as a veteran's benefit. When they separate, he will get that veteran's benefit as well as 1/2 of the SSI they received (which was already reduced by his veteran's benefit) and she will have only 1/2 of the reduced SSI benefit.

> For example, Janice Sprandel resides in Maine. She is disabled and receives SSI. Her husband, Frederick, was retired and received Social Security in the amount of $366.10. While Frederick Sprandel was not eligible for SSI, he was treated as an SSI "eligible spouse" because he was over 65. The Sprandels were treated as an eligible couple. Janice Sprandel had no income of her own but her husband's benefit reduced the couple's monthly SSI benefit to $140. When the Sprandels separated, SSA paid each of them 1/2 of the $140 for six months. This meant that Janice Sprandel had $70 to live on for each of the six months while Frederick Sprandel had not only his $366 but also $70 of SSI.

This current requirement is inconsistent with the more favorable treatment which the Secretary accords to married couples who separate where only one spouse is receiving SSI and the other's income is being deemed to the SSI recipient spouse. In those cases, the individuals are treated as separated after the first month. There is no reason to do less for the couples where both are treated as receiving SSI.

Very frequently, the women who are harmed by the current provision are victims of domestic violence who are trying to escape their abusive husbands. Without a full SSI benefit, they do not have any measure of economic wherewithal and are left to survive for six months on very little.

This provision in the bill addresses this problem very effectively: the couple will be treated as individuals after one month. For people like Mrs. Sprandel, that means that she will receive the full SSI benefit instead of struggling to survive on $70.00. Further, in those cases where the Secretary determines that there is a financial emergency, as one would expect with domestic violence or where the person is homeless or likely to become homeless soon, even the one month wait would be waived.

Section 106 of H.R. 867: Increase in face value of life insurance policies whose cash value is disregarded and increase in allowable burial fund.

It would be very helpful to raise the permissible levels on insurance policies and burial accounts. The provision also includes another significant improvement in the statute's burial account provision.

§106 provides that the overpayment rules will be applied in cases where an SSI recipient improperly uses the funds set aside for burial. Currently, if an SSI recipient makes a mistake and uses a portion of the burial trust for something other than burial, SSA does not apply its overpayment rules to the situation. Instead, it treats the person as being penalized and cuts off the person's SSI for as long as necessary to cover the amount that was spent. This works an incredible hardship on the unsuspecting SSI recipient.

For example, if Mrs. A's water heater explodes one cold night and she uses all or part of her burial account to meet this unexpected expense, SSA will withhold her entire SSI check until it recovers the full amount that she spent.

But, if the SSA was required to treat the situation like any other overpayment,the result for Mrs. A would be far less devastating. SSA would be required to inform Mrs. A that she had been overpaid and that she had the right to seek waiver of recovery of the overpayment if she believed that she was not at fault in creating the overpayment and if it would defeat equity and good conscience to require her to repay. If Mrs. A did not seek waiver or if her request was denied, SSA would recover the amount of the overpayment by withholding no more than 10% of her income monthly. While the 10% limit would not apply where fraud was involved, most cases would fall under the 10% rule if waiver was not granted.

Section 201 of H.R. 867: Continued SSI suspension status for certain residents of public mental institutions.

In the 1984 Disability Benefits Reform Act, Congress assured that disabled beneficiaries would not lose their benefits if their conditions had not medically improved (subject to certain exceptions.) This very significant clarification in the law has brought some sense of security for many beneficiaries. There are still a few problems. One is that if a disabled SSI recipient enters a public mental institution generally his SSI benefits are suspended. The suspense status lasts for 12 months. If he leaves the institution within 12 months, benefits are reinstated. However, if he stays longer than 12 months, he must reapply for SSI. Upon reapplication, SSA does not apply the medical improvement standard.

In the case of a man in Oregon, SSA denied his application despite the fact that he was just as disabled as he had been before he entered the institution. Under this provision, the suspense status would continue for the entire time that the person is in the institution. As a result, the medical improvement standard will be applied in the person's case when his case is readjudicated. The cost is insignificant but the impact for individuals like this gentleman is great.

Section 301 of H.R. 867: Retention of Medicaid when SSI benefits are lost upon entitlement to Social Security spouse benefits or retired workers benefits prior to age 65.

In recent years, the Congress has taken steps to protect certain categories of people who were receiving SSI disability benefits until SSA required them to apply for a Social Security benefit when they became eligible for the benefit. As a result of receiving the Social Security benefit, the person lost SSI and Medicaid. Unfortunately, the old age benefit which the person receives does not provide for Medicare coverage until age 65. For example, in 1987, Congress provided that a disabled widow who was receiving SSI disability before she turned age 60 who was required by SSA to apply for old age spouse's benefits at age 60 would be deemed to be SSI eligible until she was 65 so that she could continue to receive Medicaid. Without this provision, she had no health care coverage from age 60 until age 65.

This bill identifies two other groups of disabled individuals who are similarly situated to these disabled widows. Mrs. B is the disabled spouse of a very low-income worker, in this case, a farmer. Because she does not have an earnings record of her own, she is not eligible for Social Security disability benefits. Instead, she receives SSI disability. When she turns age 62 and her husband is eligible for Social Security, SSA requires her to apply for spouse's retirement benefits on her husband's record. The result is that she begins receiving Social Security and if the benefit is higher than SSI, she loses her SSI and her Medicaid. However, because she is only 62 years old, she will not be entitled to receive Medicare until she is 65. This is true even though she has already been determined to be disabled by SSA and even though she needs health care coverage. Under this bill, Mrs. B will be deemed SSI eligible until she reaches age 65. This will permit her to continue to receive Medicaid until she is eligible to begin receiving Medicare.

A similar problem currently exists for workers who become disabled but who, while they will be eligible for a retirement benefit, are not able to meet the recency of work test and therefore are not eligible for a Social Security disability benefit. These individuals, if their income and resources are low enough, receive SSI disability benefits. When these individuals become 62, SSA forces them to apply for early retirement benefits. Again, they lose SSI and Medicaid, but are not entitled to receive Medicare until age 65. Under the provision of the bill, these individuals would be deemed eligible for SSI so that they could continue to receive Medicaid from ages 62 until 65.

Section 302 of H.R. 867: Retention of Medicaid for certain additional disabled adult children.

In 1986, in Public Law 99-643, Congress recognized that some young SSI disability recipients lost SSI and, thus, their connection to the Medicaid program, when their parents died, became disabled or retired and the adult "child" became entitled to Social Security dependent's benefits as the adult disabled child of the worker. The 1986 provision says that any SSI recipient who loses SSI and Medicaid as a result of becoming entitled to Social Security disabled adult child benefits on or after July 1, 1987, will be deemed eligible for SSI so that s/he can continue to receive Medicaid.

The provision in this bill recognizes that there are others who have exactly the same problem and are no longer able to receive Medicaid who first became entitled to Social Security prior to July 1, 1987. This provision would permit

people in this group who first became entitled to Social Security between 1981 and July, 1987 to also be deemed SSI recipients and, as a result, to begin once again to receive Medicaid. This provision is particularly important to those individuals with disabilities who must be Medicaid eligible in order to secure placement in a community-based group home.

Section 303 of H.R. 867: Amendments affecting individuals considered to be receiving SSI for purposes of the Medicaid program.

There are now a number of categories of individuals who are permitted to retain Medicaid eligibility once their SSI cash benefits cease. Under the current procedures, when SSA notifies a person that his/her SSI benefits will be terminated, if the person falls into one of the protected categories, SSA generally states in the notice that the person may still be eligible for Medicaid and that the person should contact the state Medicaid agency. This sounds simple enough but it appears that, in fact, many of these individuals never are able to make the connection with the Medicaid program.

This provision will smooth the transition between the two programs. When the person loses SSI, if s/he is in one of the protected groups who are deemed to be receiving SSI for Medicaid purposes, SSA would simply notify the state Medicaid agency to change the person's Medicaid status and that they should readjudicate the person's eligibility. This would significantly ease the transition for a group of individuals who are all disabled and most of whom are also elderly. This very modest improvement is critically needed.

Section 2 of H.R. 868: Definition of disabled children

The testimony presented at the March 2, 1989 joint hearing by Bill Shelton and Donna Lefebvre very clearly explained the need for immediate statutory reform of the SSI disabled children's program. Further support is provided by the case examples which were also submitted for the record. The bottom line here is that severely disabled poor children are going without the benefits which the Congress intended them to have because of rules designed by SSA to exclude many of these children. It is important not only that the statutory definition be clarified to require that SSA properly consider all of a child's impairments and limitations but also to require SSA to update the listing of impairments which it utilizes.

It is also very important that there be a mechanism which permits the youngest disabled children who are the most difficult to test to receive benefits. Then when they are old enough, their continuing eligibility can be reassessed. The current situation is ludicrous. It is common for SSA to find that a child with Down Syndrome is eligible at age 18 months, the month in which the child could be tested, but not in the preceding months even though the child's application has been pending since shortly after birth. Playing these types of bureaucratic games with children who obviously have been disabled since birth is heartless and should be stopped.

Proposed addition to the legislation: In the 1984 disability amendments, Congress required the Secretary to make every reasonable effort to assure that all of the state disability determination services (DDSs) had a psychiatrist or psychologist on staff who was required to review all of the cases in which the person had a mental impairment. The Congress also instructed the Disability Advisory Committee to recommend whether there was a need for a greater roll for medical specialists in the DDSs. The Committee's

recommendation was that states should use their judgment when medical specialists were needed but that they should not be mandated. This ignores the fact that there are entire categories of cases in which review by a specialist could make a significant difference in the quality and accuracy of the decision issued. One such area is pediatrics. The Congress should consider expanding the language in the 1984 Act to require that the state agencies must have disabled children's cases reviewed by a board-certified pediatrician.

Section 3 of H.R. 868: Amendments related to resources

SSA's $6,000/6% rule is a serious bar to eligibility for disabled children and some disabled spouses in families where the worker is a farmer or self-employed. Under SSA's rule, SSA will only exclude income-producing property from consideration as a resource if it is worth less than $6,000 and has at least a 6% return on investment each year. For many struggling farmers, this means that they must choose between their farms and their disabled child or spouse. For example, SSA says in the preface to its regulations that because the $6,000 rule only applies to the equity value, a farmer can simply encumber his property further in order to obtain SSI benefits for the child. However, in the spring, when the farmer goes to the bank to seek a loan for the spring planting, no bank will provide a loan where the equity is so low.

When SSA published its regulation implementing the $6,000/6% rule in 1985 (it had been using it for at least a decade before the regulation was issued), it indicated that it was relying upon a study it had done in setting the figures. In response to my Freedom of Information request for a copy of the study, SSA replied in January, 1986 that, "The survey referred to in the October 22, 1985 Federal Register no longer exists. This survey was done prior to 1974, and it is the policy of the Social Security Administration to routinely purge its records of obsolete documents."

Two courts have held that the current rule is arbitrary and capricious. See Maine Association of Interdependent Neighborhoods v. Petit, 647 F.Supp. 1312 (D. Me. 1986); Hintz v. Bowen, Civil No. A1-87-89 (D.S.D. November 30, 1987).

The simple solution to the problem is the one set forth in this bill. Instead of focusing on the value of the income-producing property, SSA should focus on the income which it generates. This is very reasonable and consistent with the treatment of income-producing property in the food stamp program. It would also make a tremendous difference to individuals with disabilities and their families. Two examples will illustrate this:

> There is a man who lives in South Dakota. He has three children, all of whom have cerebral palsy. He has a one-person beauty shop in a small town with a population of under 1,000. The shop is valued at $14,680. His income last year from the shop was $5,720. His three children have been denied SSI because, under the $6,000/6% rule, his business, which yields the family's only source of income, is worth more than $6,000. If SSA was required to focus on the income generated by the family's business, instead of the value of the business, the children would be eligible both for SSI and the Medicaid which they very much need.
>
> Brian Hintz is 17 years old and mentally retarded. He lives with his parents on their farm in North Dakota. He received SSI but his benefits

were terminated because SSA found that his resources exceeded the resource level. His parents had $6,882 equity value in their livestock, machinery and vehicles. On appeal, the administrative law judge found that the family's farming operation was "barely marginal. They have an inadequate acreage basis and their machinery is old and of little use or value. It is apparent they are in need of the supplemental security income payments made to their son, Brian." However, because of the $6,000/6% rule, the ALJ found that Brian was not eligible. This decision stood until a federal district court held that the rule was arbitrary and capricious.

Section 4 of H.R. 868: SSI disabled and blind children eligible for Medicaid in all states

It surprises many people to learn that even if a disabled child is somehow able to establish eligibility for SSI, they may still not be eligible for Medicaid in some states. This is because of the §209(b) Medicaid option which fourteen states have exercised. Section 4 recognizes the critical importance which not only SSI but also Medicaid serve in addressing both the immediate and long-term health needs of the child with disabilities. Under this provision, any child who establishes eligibility for SSI would also be eligible for Medicaid, without regard to where his or her family happens to reside.

SSA's apparently imminent action to publish proposed SSI children's mental impairment listings should not distract the Congress from the need for legislation on problems facing disabled children in SSI.

It is my understanding that SSA is about to announce that it will be publishing the proposed SSI children's mental impairment listings. This action comes only after three years of delay and a great deal of pressure from the Congress. Given this hearing, and the Chair's publicly-stated concern for SSI disabled children and co-sponsorship of H.R. 868, SSA's timing is, at best, suspect. It is critical that this Subcommittee not permit this action to derail the SSI disabled children's legislative initiatives. Even if the proposed listing changes are satisfactory, which remains to be determined, they will not resolve the problems which disabled children face if they are physically impaired or if SSA otherwises persists in its refusal to consider functional limitations. They also will not solve the problems created by SSA's very restrictive resource rules nor the lack of access to Medicaid in §209(b) states.

Disabled people who receive Social Security benefits need this Subcommittee's help to secure statutory protections so that they can attempt to return to work.

Since 1986, due to the efforts of this Subcommittee, there has been an excellent work incentive program in SSI. Under §1619(a) and (b), it is now possible for an SSI disability recipient to go to work and receive a reduced SSI benefit and, even if no cash benefit is available due to higher earnings, continue to be eligible for Medicaid. There is no comparable program for Social Security disability beneficiaries despite the fact that they have virtually identical needs.

H.R. 8 is an effort to create a procedure parallel to §1619 for Social Security disability beneficiaries. As you are aware, a somewhat different, less expensive package has been devised. Under the proposed package, different rules would apply to those who receive benefits as a disabled

adult child (DAC) than would apply to those receiving worker's benefits. Under the proposal, disabled workers would have the option of moving into §1619(a) and (b) when they have returned to work and have exhausted their eligibility for Social Security benefits, if their resources are below the SSI level and the person otherwise meets the requirements of the SSI program.

This proposal is a modest effort to address a critical need in Social Security. I urge the members of this Subcommittee to take the steps to assure that the SSI portion of the package can be linked-up with the Social Security portion at the full Committee's mark-up next month.

<u>This Subcommittee should consider codifying a complete set of SSA's current rules on what is not considered to be "income" or a "resource" for SSI purposes</u>.

It is a fairly well-kept secret at SSA that there are steps that someone can take to assist an SSI recipient which will not affect the person's eligibility for benefits. While some of these rules appear in SSA's regulations, they are scattered and some are fairly obtusely written. For example, under "bills paid for you," 20 C.F.R. §416.1103(g), SSA states that the payment of bills by someone else directly to the supplier is not income. [However, the value is counted if it is food, shelter, clothing.] SSA then minimizes the importance of this rule by providing an example where a relative pays to have the SSI recipients' lawn mowed.

An even better-kept secret is that SSA takes a limited view of what constitutes "shelter". 20 C.F.R. §416.1130(b) says "shelter" "includes room, rent, mortgage payments, real property taxes, heating fuel, gas, electricity, water, sewerage, and garbage collection." Advocates have always read "includes" to be "includes, but is not limited to." SSA staff say they read it as "includes only." SSA's interpretation is obviously more beneficial. It permits payment by others of items such as home repairs and telephone bills without impairing SSI eligibility.

It costs nothing to codify SSA's current rules on these matters.[2] Yet, it would make a big difference for SSI recipients. By codifying SSA's current rules, there would be clear public notice of what the rules are and some certainty about what steps can be taken to assist an SSI recipient. The net result will be an improvement in the quality of life for at least some SSI recipients.

<u>Conclusion</u>

As always, this Subcommittee is uniquely positioned to improve the circumstances of low-income elderly and disabled individuals in the SSI program. There are excellent options, some of which are not very expensive and hopefully can be enacted very soon. For the more expensive improvements, it would greatly benefit low-income elderly and disabled individuals if the Subcommittee could identify and act upon at least incremental steps toward raising both the benefit level and the assets test.

Thank you for considering this statement.

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2. H.R. 71 is a more ambitious solution to these concerns. However, due to the cost of H.R. 71, it seems most desirable to simply organize all of SSA's rules in one place and provide SSI recipients with a useful notice of the current rules.

Acting Chairman DOWNEY. Bishop Moore

STATEMENT OF MOST REV. EMERSON J. MOORE, AUXILLIARY BISHOP FOR THE ARCHDIOCESE OF NEW YORK, ON BEHALF OF THE UNITED STATES CATHOLIC CONFERENCE, CATHOLIC CHARITIES USA, AND THE NATIONAL CATHOLIC OFFICE FOR PERSONS WITH DISABILITIES

Rev. EMERSON MOORE. Thank you. My name is Bishop Emerson Moore, and I am here today on behalf of the Nation's Roman Catholic bishops and also on behalf of Catholic Charities U.S.A., which represents the largest network of voluntary social services agencies in our country. Today I am also speaking for the National Catholic Office for Persons with Disabilities, the pastoral and advocacy voice for 8 million Catholics with disabilities.

I am here to ask for early action on proposed SSI legislation that would accomplish three important goals:

First, the establishment of a national minimum income floor for elderly and disabled people at no less than the poverty line; second, the repeal or revision of many statutory and regulatory obstacles to aid for some of the most vulnerable people in our society; and third, the creation of a serious outreach effort to provide SSI and Medicaid benefits to the many elderly and disabled people living in poverty and deprivation.

The interest of the Catholic Church in these matters is not new. As early as 1919, in their "program of social reconstruction", the bishops called for a national system of social insurance to provide protection against old age, disability and illness. Through the intervening years, the church has been a strong and vocal supporter of a national minimum income for those who are not able to provide for themselves an adequate standard of living.

More recently, Cardinal John J. O'Connor, the Archbishop of New York, the diocese in which I serve, met with former Secretary of Health and Human Services, Margaret Heckler, to request action by the Social Security Administration [SSA] to provide SSI to the many homeless persons with mental and physical impairments. Subsequently, SSA has taken many important steps to improve their service to disabled homeless people.

The church has also repeatedly asked this subcommittee to prevent the Social Security Administration from reducing SSI benefits or denying aid altogether to elderly and disabled persons who receive in-kind aid from churches and other nonprofit organizations. We were very pleased when the Congress enacted a permanent prohibition of that policy.

The recent and current experience of Catholic parishes, dioceses and agencies with the SSI program is with its failures. Frequently, our assistance to elderly and disabled people comes in periods of crisis—crises that could have been avoided had the SSI program served its purpose.

In general, these crises arise for three reasons:

First, the income, including SSI, of a disabled or elderly person is not enough to pay rent even for the cheapest available lodgings and still have money left for food and other necessities. The church is faced with the need to house or feed or otherwise assist these

people. These are needs far beyond our resources, and so we find ourselves operating shelters and soup kitchens for people who ought to have meals in their own homes. Even in States that supplement the Federal benefit, very few individuals can live in dignity at the current SSI level.

SSI, after all, is a program for people who are not able to work because of age or infirmity. One has to question the morality of a Government policy that provides a maximum benefit for such people below the official poverty line.

The second set of problems with SSI is the Kafkaesque body of rules and regulations that make many very poor people ineligible for SSI. The current rules for someone living in the household of another are counterproductive. For example, SSI rules discourage families from providing direct personal assistance to their poor elderly and disabled family members. Providing a home for a destitute 62 year-old cousin or a mentally disabled nephew could leave her or him with one-third less income from SSI or even disqualify the individual from SSI and, therefore, from Medicaid. The loss of Medicaid coverage for an elderly or disabled person will almost certainly result in very serious health consequences when prescriptions aren't refilled, medical appointments are postponed, and other essential treatment cannot be paid for.

The current rules that apply to severely disabled children can often be cruel. Too often, children do not receive the medical and rehabilitative services they need because the state of the art disability testing of children does not measure up to the standards of the Social Security Administration.

Still other disabled children do not qualify for SSI until their parents have exhausted resources that should have been saved to meet the needs of other children in the family. The SSI resources limits, as applied to such families, have the effect of denying all help to a child with a severe birth defect, such a spina bifida or profound retardation, unless his or her parents first use up the money they were saving for the needs of brothers and sisters, such as braces and school tuition.

In addition to changes needed in the application of resources limits to disabled children and their families, the resources limits generally need revision. Mr. Chairman, there are other problems I don't have time to address. Our priorities however are one, raising the minimum national benefit to at least the poverty level, two, encouraging family care of elderly and disabled persons, especially disabled children, by changing the treatment of in-kind support and family resources; and three, reaching out to the many who need help but don't know where to turn.

Thank you.

Acting Chairman DOWNEY. Thank you. Mr. Carranco.

[The statement of Bishop Emerson Moore follows:]

STATEMENT OF MOST REV. EMERSON J. MOORE
AUXILIARY BISHOP OF NEW YORK ON BEHALF OF
U.S. CATHOLIC CONFERENCE
CATHOLIC CHARITIES U.S.A.
NATIONAL CATHOLIC OFFICE FOR PERSONS WITH DISABILITIES

TESTIMONY ON PROPOSED SSI LEGISLATION

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1) The income, including SSI, of a disabled or elderly person is not enough to pay rent even for the cheapest available lodgings and still have money left for food and other necessities. The Church is faced with the need to house or feed or otherwise assist these people. These are needs far beyond our resources, and so we find ourselves operating shelters and soup kitchens for people who ought to have meals in their own homes. Even in states that implement the federal benefit, very few individuals can live in dignity at the current SSI level.

SSI, after all, is a program for people who are not able to work because of age or infirmity. One has to question the morality of a government policy that provides a maximum benefit for such people below the official poverty line.

2) The second set of problems with SSI is the Kafkaesque body of rules and regulations that make many very poor people ineligible for SSI. The current rules for someone living in the household of another are counterproductive. For example, SSI rules discourage families from providing direct personal assistance to their poor elderly and disabled family members. Providing a home for a destitute 62 year-old cousin or a mentally disabled nephew could leave her or him with one-third less income from SSI or even disqualify the individual from SSI and, therefore, from Medicaid. The loss of Medicaid coverage for an elderly or disabled person will almost certainly result in very serious health consequences when prescriptions aren't refilled, medical appointments are postponed, and other essential treatment cannot be paid for.

The current rules that apply to severely disabled children can often be cruel. Too often, children do not receive the medical and rehabilitative services they need because the state of the art of disability testing of children does not measure up to the standards of the Social Security Administration.

Still other disabled children do not qualify for SSI until their parents have exhausted resources that should have been saved to meet the needs of other children in the family. The SSI resources limits, as applied to such families, have the effect of denying all help to a child with a severe birth defect, such as spina bifida or profound retardation, unless his or her parents first use up the money they were saving for the needs of brothers and sisters, such as braces and school tuition.

In addition to changes needed in the application of resources limits to disabled children and their families, the resources limits generally need revision. While SSI limits are not as stingy as those for AFDC families, they are still too low. The limits on life insurance policies and burial funds are particulary worrisome to the elderly poor whose last hope of dignity is often a decent funeral and burial.

3) The third major flaw in the SSI program is that those who most need aid don't know that they are eligible. The Social Security Administration has not done the job itself, nor has it provided helpful tools for outreach by voluntary agencies. Outreach is especially needed to the families of severely disabled children. Their decisions about the treatment of newborns or the placement of children in institutions or foster care are usually made in the absence of any information about the availability of SSI and Medicaid.

A major effort is needed to educate administrators and staff in hospitals, clinics, and private agencies about SSI and its connection to Medicaid so that they can inform their patients and clients. Such an effort might even save money that is now spent on shelters, soup kitchens, hospitals, nursing homes and other institutions. Even more important, cash and medical assistance, provided in a timely manner, would reduce needless suffering.

Mr. Chairman, there are some other problems with the SSI program that I don't have the time or the technical expertise to discuss. Many of them are addressed in the three bills before you that were introduced by Mr. Matsui. However, our priorities are:

1) raising the minimum national benefit to at least the poverty level;

2) encouraging family care of elderly and disabled persons, especially disabled children, by changing the treatment of in-kind support and family resources; and

3) reaching out to the many who need help but don't know where to turn.

In the words of Pope John XXIII in his encyclical, Peace on Earth:

> Every person has the right to life, to bodily integrity, and to the means which are suitable for the proper development of life... Therefore, a human being has the right to security in case of sickness, inability to work, widowhood, old age, unemployment; or whenever through no fault of his own he is deprived of the means of his livelihood.

As John XXIII and his successors have continued to point out, only government has the power and the resources to make these rights a reality. In our society, it is clearly the responsibility of the federal government to ensure that these rights are protected in every state. On behalf of the Catholic bishops, Catholic social service and advocacy agencies throughout the country, I urge you to act quickly to protect the rights and dignity of our elderly and disabled brothers and sisters.

STATEMENT OF FRANCISCO CARRANCO, MEMBER, BOARD OF DIRECTORS, AMERICAN ASSOCIATION OF RETIRED PERSONS

Mr. CARRANCO. Thank you. AARP appreciates the opportunity to testify on one of its priority issues, SSI reform. The association commends the chairman and members of this subcommittee for their hearings on this matter.

It is a personal privilege for me to represent the AARP on this subject. Not only have I participated in their outreach, but in my home town of Laredo, Tex., I have observed poverty during the last 9 years as a volunteer.

The association commends the chairman's leadership and interest in this important matter. As for myself, I was present on April 14, 1989, when you addressed an impressive group of interested and dedicated Americans meeting for the explicit purpose of examining the SSI program. Your efforts are sincerely appreciated. I am certain you will hear many recommendations for reform of this program but not any as basic as increasing the benefit level.

The incidence of poverty among many subgroups of the elderly is shocking. For example, according to Census Bureau data for 1987, 33.9 percent of all black persons 65 and over lived in poverty. Older black women experienced a 40.2-percent poverty rate, while for older black males the rate was 24.6 percent.

SSI recipients are among the poorest of the poor. Since the Federal cash assistance provided is less than the Federal poverty level, SSI recipients—especially those in States that do not adequately supplement the Federal benefit level—live on less than a subsistence level of income.

This committee has previously heard testimony from an SSI recipient regarding financial difficulties she faces because of the limited income SSI provides. The struggles Ms. Brown-Bey described should not have to take place in a nation as rich as ours.

AARP supports increasing the Federal SSI monthly benefit. H.R. 361 and H.R. 866 provide for a 3 year, phased-in increase in the monthly benefits for individuals and couples to the poverty level. If the legislation were enacted, an individual's monthly benefit amount would rise from its current level of $368 to approximately $575 in 1992. Similarly, the current monthly benefit for a couple would increase from $553 to $770. The first year costs would be $2 to $3 billion, including the cost of additional Medicaid benefits and savings from food stamp reductions.

Included among the provisions of H.R. 866 and H.R. 867 are changes in the definition of, or limits on the types and sources of income that a SSI recipient may receive. AARP supports the provision in H.R. 867 that would, first, change the treatment of workmen's compensation and unemployment compensation, second, annualize biweekly and/or weekly income, third, disregard the value of domestic air, bus, and train tickets, fourth, disregard certain interest and dividend income, and fifth, reduce the time period during which income and resources are treated as jointly held by couples who have separated.

These changes are not very costly compared with the protection SSI recipients would receive. The Congressional Budget Office estimates that together these changes would cost $10 million. If these

changes are not made, SSI recipients will continue to be punished for overpayments because of the resulting income. For instance, if an SSI recipient accepts an airline ticket to attend the funeral of a family member, the value of that ticket is defined as "income". This results in lost benefits, or worse yet, SSA seeking a return of funds because of an overpayment. The provision in H.R. 867 mentioned above would stop this situation, and the other provisions cited would have equally salutary effects.

Another unfortunate situation occurs when interest is paid on an SSI recipient's bank account, such as a burial fund. This results in a loss of benefits because the recipient has too much income. H.R. 867 proposes a meager interest and dividend disregard—$120 for 1990—to protect the eligibility status of many needy SSI recipients. The association urges the committee to adopt this provision.

Another problem regarding income is the assignment of a one-third benefit reduction for the value of in-kind income that an SSI recipient receives when living in the household of another. Although the proportion of SSI recipients whose benefit level standards are reduced because they live in the household of another is low, those affected are hurt because they do not receive a full benefit. For instance, in March 1989, 5,516 couples (4.7 percent); 2,643 married persons living with spouses who do not receive SSI (6.4 percent); and 63,521 single persons (5.7 percent) who received SSI benefits on the basis of age, had their benefit standards reduced by one-third.

Since the Social Security Administration currently allows SSI recipients to challenge the one-third presumption for in-kind support received from persons with whom they do not live, it seems that the same privilege, provided for in H.R. 867, should be accorded to those "living in another person's household and receiving support and maintenance in-kind from such person."

AARP believes H.R. 867 highlights the equity problem created by the one-third reduction. However, the committee should be aware that alternative calculations for the one-third reduction may be difficult because the assistance provided when living in the home of another is not easily valued in the marketplace.

Unfortunately many of those whose monthly income is sufficiently low to qualify for an SSI benefit are excluded from the program because their countable assets exceed the allowable limit of $2,000 for an individual or $3,000 for married couples. Although certain assets, such as a home and wedding rings are excluded, it is very difficult for poor persons to meet the eligibility criteria that were developed in 1972. Excluded assets under SSI are more narrowly defined than in other means-tested programs such as food stamps. Although Congress in 1984 adopted a one-time, phased-in increase of the asset levels, the threshold still remains below what it would have been if indexed for inflation since the programs inception.

A study conducted for AARP by the Policy Center on Aging of Brandeis University found that adjusting the original assets level for inflation as in H.R. 360 and H.R 866 would increase the aged participation rate by 6 percent. The small increase reflects the minimal nature of the increase proposed in H.R. 866 and H.R. 360.

Clearly a further liberalization of the assets test is needed at this time, and it should be annually updated for inflation. These

changes would be of considerable assistance to persons of all ages who are excluded from the program because they or a family member have accumulated meager assets.

AARP believes Congress also should modify the treatment of certain types of resources that determine SSI eligibility.

Although not affecting as many persons as an adjustment of the assets test for inflation, these changes would be of enormous benefit to those harmed by current law.

AARP recommends that the disregard value of life insurance be increased to $2,500 as provided in H.R. 867. Currently a person can have a life insurance policy with a face value only up to $1,500 and not have that counted as an asset for SSI eligibility purposes. The association also recommends that the burial fund limit be increased in tandem with increase in the face value of life insurance. New rules, such as those proposed in H.R. 867, regarding recovery or waiver of overpayments for cases where the person mistakenly uses a portion of the burial account are also needed. These new rules would protect the eligibility of SSI recipients who do not understand the complexity of the many restrictions concerning such assets.

The association finds that aged poor persons are also affected by the "$6,000/6-percent rule" regarding the value of resources that generate income. For instance, many older farm couples are prevented from participation in SSI because of this rule. Because of depressed farm prices they are unable to receive the required 6-percent minimal return on their farm assets and, therefore cannot meet the 6-percent rule. Also, many black farmers in the South are disqualified because their name appears on "heir" farmland that belongs to several family members. AARP recommends that the elimination of the $6,000/6-percent rule, as proposed in H.R. 868, should encompass the entire SSI population and not be limited to disabled and blind children.

Our written testimony elaborates details of AARP's outreach program. The association is pleased with the effectiveness of its 1988 demonstration project in El Paso, Oklahoma City and Pittsburgh. It gives me much satisfaction to present the following final results of that effort. An unprecedented success rate of 97-percent increase in applications and 58-percent increase in awards. Our success is making a big difference in the lives of many today.

Our 1989 10-site expansion has started and even more is in the planning stage. Also, AARP is developing a how-to manual and video tape to enable interested communities to develop outreach activities on their own.

AARP's outreach, while successful, is not a substitute for the outreach provision in H.R. 866, the legislation addresses the national need for federally funded outreach by the Social Security Administration and by private groups. Those who know about SSI, but whose income is sufficiently low cannot qualify because they have accumulated some assets. AARP supports H.R. 361 and the provisions in H.R. 866 to increase the assets limit to the level it would have reached if it had been adjusted for inflation.

Our testimony mentions various provisions in H.R. 867 which would change the current treatment of certain types and sources of income. These provisions are not costly and their enactment would

make a big difference to those who were hurt by the current law. AARP recognizes that the current one-third reduction for living in the home of another needs to be changed.

It is a barrier to care giving and in-home assistance to the disabled. Those who do not receive SSI because of this reduction should be at least entitled to receive Medicaid. In addition, there are others who lose SSI when they become eligible for early retirement Social Security benefits. As a result, they are no longer eligible for Medicaid. They are left in a medical limbo until they become eligible for Medicare at age 65.

We support the provision in H.R. 867 deeming such persons Medicaid eligible.

In conclusion, SSI is a family program, yet very few improvements have been made to it since it was enacted in 1974. We must not allow the years of neglect to continue indefinitely. AARP is prepared to work with the committee in developing legislation to assist the poor, elderly, blind and disabled.

Thank you.

Acting Chairman DOWNEY. Thank you.

[The statement of Francisco Carranco follows:]

STATEMENT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS

The American Association of Retired Persons appreciates the opportunity to testify on the Supplemental Security Income (SSI). The Association believes that improvement and expansion of SSI is vital to reducing poverty among low-income persons, and it has made SSI reform a top priority in this Congress. We appreciate the chairman's leadership in seeking badly needed improvements to the SSI program.

* * * *

Implemented in 1974 to reduce poverty among the poor aged, blind and disabled, SSI provides a modest monthly cash benefit to eligible low-income persons. To qualify individuals must have very little income and also must meet a stringent asset test. The program is administered by the Social Security Administration (SSA) and funded out of general revenues.

Since 1974, Congress has made some improvements in the SSI program. As a result, some unduly restrictive eligibility requirements were removed and a modest benefit improvement implemented. However, additional reforms are needed to make the program more accessible and to significantly reduce some of the burdens of poverty among the aged, blind, and disabled. The most significant changes are

- o increasing the federal benefit level;
- o raising the assets limits to reflect growth in the economy; and
- o an aggressive outreach effort so that all SSI-eligible persons know about and can participate in the program.

I. Benefit Standards

The incidence of poverty among many subgroups of the elderly is shocking. For example, according to Census Bureau data for 1987, 33.9 percent of all black persons 65 and over lived in poverty. Older black women experienced a 40.2 percent poverty rate, while for older black males the rate was 24.6 percent.

SSI recipients are among the poorest of the poor. Since the federal cash assistance provided is less than the federal poverty level, SSI recipients--especially those in states that do not adequately supplement the federal benefit level--live on less than a subsistence level of income.

This committee has already heard testimony from an SSI recipient regarding financial difficulties she faces because of the limited income SSI provides. The struggles Ms. Brown-Bey described should not have to take place in a nation as rich as ours.

AARP supports increasing the federal SSI monthly benefit. H.R. 361 and H.R. 866 provide for a three year, phased-in increase in the monthly benefits for individuals and couples to the poverty level. If the legislation were enacted, an individual's monthly benefit amount would rise from its current level of $368 to approximately $575 in 1992. Similarly, the current monthly benefit for a couple would increase from $553 to $770. The first year costs would be $2 to $3 billion, including the cost of additional Medicaid benefits and savings from food stamp reductions.

II. Changing Income Definition

Included among the provisions of H.R. 866 and H.R. 867 are changes in the definition of, or limits on the types and sources of income that a SSI recipient may receive. AARP supports the provisions in H.R. 867 that would (1) change the treatment of workmen's compensation and unemployment compensation, (2) annualize biweekly and/or weekly income, (3) disregard the value of domestic air, bus, and train tickets, (4) disregard certain interest and dividend income, and (5) reduce the time period during which income and resources are treated as jointly held by couples who have separated.

These changes are not very costly compared with the protection SSI recipients would receive. The Congressional Budget Office estimates that together these changes would cost $10 million. If these changes are not made, SSI recipients will continue to be punished for "overpayments" because of the

resulting income. For instance, if an SSI recipient accepts an airline ticket to attend the funeral of a family member, the value of that ticket is defined as "income". This results in lost benefits, or worse yet, SSA seeking a return of funds because of an overpayment. The provision in HR 867 mentioned above would stop this situation and the others cited would have equally salutary effects.

Another unfortunate situation occurs when interest is paid on an SSI recipient's bank account, such as a burial fund. This results in a loss of benefits because the recipient has too much income. HR 867 proposes a meager interest and dividend disregard ($120 for 1990) to protect the eligibility status of many needy SSI recipients. The Association urges the committee to adopt this provision.

Another problem regarding income is the assignment of a one-third benefit reduction for the value of in-kind income that an SSI recipient receives when living in the household of another. Although the proportion of SSI recipients whose benefit level standards are reduced because they live in the household of another is low, those affected are hurt because they do not receive a full benefit. For instance, in March 1989, 5,516 couples (4.7%); 2,643 married persons living with spouses who do not receive SSI (6.4%); and 63,521 single persons (5.7%) who received SSI benefits on the basis of age, had their benefit standards reduced by one-third.

Since the Social Security Administration currently allows SSI recipients to challenge the one-third presumption for in-kind support received from persons with whom they do not live, it seems that the same privilege, provided for in H.R. 867 should be accorded to those "living in another person's household and receiving support and maintenance in-kind from such person".

AARP believes H.R. 867 highlights the equity problem created by the one-third reduction. However, the committee should be aware that alternative calculations for the one-third reduction may be difficult because the assistance provided when living in the home of another is not easily valued in the marketplace.

III. Resource Limits

Unfortunately many of those whose monthly income is sufficiently low to qualify for an SSI benefit are excluded from the program because their "countable" assets exceed the allowable limit of $2,000 for an individual or $3,000 for married couples. Although certain assets, such as a home and wedding rings are excluded, it is very difficult for poor persons to meet the eligibility criteria that were developed in 1972. Excluded assets under SSI are more narrowly defined than in other means-tested programs such as food stamps. Although Congress in 1984 adopted a one-time, phased-in increase of the asset levels, the threshold still remains below what it would have been if indexed for inflation since the program's inception.

A study conducted for AARP by the Policy Center on Aging of Brandeis University found that adjusting the original assets level for inflation as in H.R. 360 and H.R. 866 would increase the aged participation rate by 6 percent. The small increase reflects the minimal nature of the increase proposed in H.R. 866 and H. R. 360.

Clearly a further liberalization of the assets test is needed at this time and it should be annually updated for inflation. These changes would be of considerable assistance to persons of all ages who are excluded from the program because they or a family member have accumulated meager assets.

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The Association finds that aged poor persons are also affected by the "$6,000/6% rule" regarding the value of resources that generate income. For instance, many older farm couples are prevented from participation in SSI because of this rule. Because of depressed farm prices they are unable to receive the required 6% minimal return on their farm assets and, therefore are excluded from.ices prevent them from meeting the 6 percent rule. Also, many black farmers in the South are disqualified because their name appears on "heir" farmland that belongs to several family members. AARP recommends that the elimination of the $6,000/6% rule, as proposed in H.R. 868, should be encompass the entire SSI population and not be limited to disabled and blind children.

IV. Participation and Outreach

A. Participation Rates

There are now 4.4 million SSI recipients. Many millions of desperately poor people could participate if they knew about the program.

Since 1974 there have been a number of studies/reports that have analyzed the "participation rates" for the SSI program. While there are some variations in the findings, most agree that the SSI participation rate for those 65 and over is only between 50 and 60 percent.

In 1988, Louis Harris and Associates surveyed 576 persons age 65 and over, who were either below or near the poverty line. Those who seemed to be eligible for SSI were asked why they had not applied. The major reason cited by 36 percent was that they were unaware of the program or unfamiliar with the eligibility requirements. Of the elderly poor, only 37 percent even knew what office to go to apply for SSI. The survey also found that only 39 percent of the poor knew of the link between SSI and Medicaid. These findings dramatically illustrate that the need still exists for widely disseminating correct information about the SSI program.

B. Outreach

Over the years, the Social Security Administration has attempted some SSI outreach efforts. The most recent SSA outreach activity came as a result of Public Law 98-21 which directed the agency to conduct two outreach efforts aimed at potential aged SSI recipients. Beginning in July 1983, a continuing monthly alert has resulted in about 2,000 new awards each month. In addition, between February and June 1984, a one-time alert was mailed to 7.6 million Social Security beneficiaries who were 65 and over and whose benefits were low enough to indicate possible SSI eligibility. This one-time effort resulted in 58,000 new SSI awards (.07% of the alerts mailed). This approach is limited in its effectiveness because it only reaches those who are currently receiving Social Security benefits and are literate and educated enough to take the appropriate action.

Also, over the past ten years there have been some scattered SSI outreach efforts. Unfortunately, most of these projects have been poorly funded, short lived, and not sufficiently documented.

C. AARP's Outreach Effort

In 1988 AARP, with funding provided by the Commonwealth Fund, Commission on Elderly People Living Alone, launched a

pilot project in El Paso, Texas; Pittsburgh, Pennsylvania; and Oklahoma City, Oklahoma to demonstrate methods of conducting successful SSI outreach activities. In each of these cities, AARP, with the active cooperation of the local area agency on aging, formed a coalition to assist with the demonstration project.

In view of the success in 1988 and to further analyze the most successful outreach methods (detailed below), AARP expanded its program to 10 new sites in 1989. This spring we are working with Sacramento, California; Asheville, North Carolina; San Antonio, Texas; Rutland, Vermont; and Lac du Flambeau, Wisconsin. This fall, we will add 5 more sites: Denver, Colorado; Winter Park, Florida; St. Paul, Minnesota; East Orange, New Jersey; and Portland, Oregon.

The major methods employed in our 1988 outreach effort have included extensive use of the media, training of volunteer SSI advocates, conducting community education presentations, and one-to-one counseling of potential applicants. Statistics provided by SSA show that overall SSI applications and awards increased dramatically. The application rate in the three cities increased by 97 percent and awards increased by 58 percent as compared to the previous three years.

Some of the conclusions from the 1988 outreach projects that we are utilizing now are

1. **Coalition Approach**
   A coalition of agencies provides the type of broad-based effort necessary to reach the elderly poor. Such groups include the area agency on aging, information and referral agencies, religious organizations, health care providers, utility companies, advocacy organizations and service providers for the elderly and disabled.

2. **Leadership of One Agency to Coordinate the Outreach Efforts**
   It is crucial that one agency take a leadership role. In 1988, the local area agency on aging in each test city served as the co-sponsor of the outreach effort. In 1989 AARP has entered into agreements with a variety of agencies in addition to area agencies on aging who will serve as local cosponsors. These include advocacy groups, minority organizations, and information and referral agencies.

3. **Variety of Outreach Methods**
   Use of the broadcast and print media is critical. However, media alone is not sufficient. Outreach must also involve training, community education presentations, and individual outreach on a one-to-one basis by those who have direct contact with the elderly.

4. **Training and Community Education**
   The eligibility requirements for SSI are complex and changeable. It is important to have ongoing training of advocates who can assist with public benefit issues in general and SSI in particular. Also, on an ongoing basis, current benefit information should be brought to the attention of potential recipients.

5. **Involvement of the Agency Administering the Program**
   The outreach project will be more successful if there is cooperation with the agency administering the program on the local level. The SSA district offices in each of the "pilot" cities cooperated with AARP and the area agency on aging. They assisted with training programs, provided materials, and suggested outreach techniques. We are pleased that the local SSA District Office in Rutland, Vermont has become a sponsoring agency.

6. **Follow-up of Individuals Referred to Social Security**
Many groups that conduct outreach activities see their job as complete after a referral is made to SSA. The AARP project found that there was a much greater chance of a successful application being filed if there was some follow-up by the agency referring the individual to SSA to make sure the appropriate action was taken.

7. **Outreach to Minority and Non-English Speaking Populations**
Special attention must be paid to informing those not reached through traditional methods of outreach. For example, in El Paso, Texas a large portion of the population responding to the SSI outreach efforts were Hispanics. Outreach to this community included working with local church groups, using the Spanish language TV and radio stations, translating training materials and videotapes into Spanish and using a bilingual outreach worker in the area agency on aging to answer SSI inquiries. In 1989, AARP will be expanding the demonstration project to other minority populations: Blacks in East Orange, New Jersey and native Americans in Wisconsin.

8. **Medicaid Eligibility**
Advocates need to emphasize the linkage between SSI and Medicaid because many potential applicants to not know about it. The availability of Medicaid can serve as an incentive to apply for SSI even though the monthly cash benefit may be low.

9. **Documentation and Evaluation of Outreach Activities**
Outreach sponsors should attempt to document their activities so others do not have to "reinvent the wheel". In addition, the success of the project should be evaluated. This evaluation should include not only a statistical analysis of the impact on applications and awards, but also on the relationships among agencies that are established as a result of these outreach activities.

D. Future

AARP hopes to continue to expand its SSI outreach program in order to assure that future SSI projects can be conducted effectively. AARP is developing an SSI "How To" Manual and videotape. These materials will provide interested communities with options for establishing their own SSI outreach. AARP will be available to provide technical assistance.

While AARP is pleased with the effectiveness of its outreach efforts, the Association recognizes that voluntary efforts cannot meet a national need. The Social Security Administration is the appropriate agency to conduct ongoing outreach activities. Therefore, we support the provisions in HR 866 mandating outreach activities. Funded by Congress, these outreach efforts would include SSA collaboration with voluntary agencies.

V. Medicaid Eligibility

Not all SSI recipients are fortunate enough to be eligible for Medicaid. Fourteen states use the 209(b) option for Medicaid that allows them to impose Medicaid eligibility criteria that are more restrictive than SSI criteria. About 22 percent of the SSI recipient population nationwide lives in these 209(b) states. Many other poor persons are caught in bureaucratic rules that prohibit them from being Medicaid eligible. For example, when a person loses SSI cash benefits but is in one of the categories of persons who are deemed to be still receiving SSI so he/she can be eligible for Medicaid, there is a gap in Medicaid coverage until that person actually goes to the Medicaid office to file an

application.

The Association supports the provisions in H.R. 866, H.R. 867, and H.R. 868 that protect those who do not receive Medicaid now. Specifically, AARP endorses the extension of Medicaid eligibility to SSI recipients living in 209(b) states and those who are not eligible for SSI because the one-third reduction in benefit standard is imposed on them since they live in the household of another.

Another group that needs to be deemed Medicaid eligible are those who lose SSI status when they turn 62 years old and are eligible for early Social Security retirement or spousal benefits. These individuals have no medical coverage until they turn 65 years old and become eligible for Medicare. Other groups whose need for Medicaid status is recognized in the proposed legislation include SSI recipient children and disabled adult children. AARP believes that extending Medicaid to all these individuals is both reasonable and affordable, and there is precedent for doing so.

VI. Conclusion

AARP believes Congress should move forward in reforming and expanding SSI. Toward that end, we are prepared to work with this committee in promoting legislation that will help reduce poverty among the poor elderly, blind, and disabled.

Acting Chairman DOWNEY. I want to thank all the panelists. We are going to try our best this term to expand modestly supplemental security income. We are not going to be able to increase it to the poverty level all at once although that is certainly our goal over time.

The outreach question is a priority with us. I think if we were to muse together, there is probably a good reason why the administration over the years has been reluctant to look for more SSI eligible people because they did not want to cover the costs.

Mr. FLEMMING. Opposition to it is built into the system, so to speak.

Acting Chairman DOWNEY. Yes. Thank you.

Our last and certainly not least panel, the National Head Injury Foundation, Gregory O'Shanick, M.D., chair of Psychiatric Task Force and professor, Department of Psychiatry, Medical College, University of Richmond; James Gashel, director of governmental affairs, National Federation of the Blind; Ralph Moore, member, Governmental Affairs Committee, Association for Retarded Citizens of the United States; Christy Disher, president, National Mental Health Consumers Association; National Alliance for the Mentally Ill; Jean Little, chairperson, SSI, SSDI Committee, New York State Alliance for the Mentally Ill; Sydney Hickey, director of government relations, National Military Family Association, National Military Family Association, Non-Commissioned Officers Association of the United States of America; accompanied by C.A. (Mack) McKinney, legislative counsel, Non-Commissioned Officers Association of the United States of America.

My colleague, Mr. Andrews, is going to chair the subcommittee for a few minutes while I make some phone calls.

We will begin with Mr. O'Shanick.

STATEMENT OF GREGORY O'SHANICK, M.D., CHAIR, PSYCHIATRIC ADVISORY COMMITTEE, NATIONAL HEAD INJURY FOUNDATION, AND ASSOCIATE PROFESSOR, DEPARTMENT OF PSYCHIATRY AND REHABILITATION MEDICINE, MEDICAL COLLEGE OF VIRGINIA, RICHMOND, VIRGINIA

Dr. O'SHANICK. Thank you, Mr. Chairman. I am very appreciative of the opportunity to speak to the subcommittee regarding a request for changes in the supplemental security listings for individuals with traumatic brain injury. I have a video tape that is entitled "Traumatic Brain Injury: Effective Diagnosis and Treatment", which I will provide to the subcommittee for its perusal. Also you have the formal text of the testimony provided by us as well.

In essence, what I want to do in the brief time I have this afternoon is to discuss what is really a great equalizer. You may not have in your family background the predilection toward cancer or heart disease, but literally any one of us in this room can walk outside and be struck by a car, fall down a flight of stairs or slip on the pavement and, in that second, sustaining a head injury, find our lives permanently changed.

Anyone can sustain traumatic brain injury. The consequences can vary from most obvious physical changes such as seen in

former Press Secretary James Brady to minor behavior or interpersonal dysfunction some of which are illustrated on the videotape.

One of the key issues is that head injury cuts across age lines. We have heard testimony in terms of children with development disability, geriatrics, et cetera. Head injury can be implicated as a causal factor at dysfunction at any age.

The peak time for TBI among young males is 15 to 24 years, right at the time when they are initiating, their educational or vocational careers. We know that among the military service at this time that traumatic brain injury ranks as the number 1 reason for service-connected disabilities.

The primary problem caused by traumatic brain injury is diffuse axonal injury which is the widespread disconnection of nerve cells from one another.

To give an example, if you were to take the phone lines going from Washington, D.C. to New York City and randomly cut every third or fourth line, and if you were to try to place a phone call between the two cities at 2 in the morning, you generally would have no problem getting the call through the first time.

If you were to call this afternoon when there was competing traffic, you might have delays, you may be rerouted through a circuit through Philadelphia or Pittsburgh which would make the connection more tenuous.

If you were trying to call on election day you may, if you got through at all, find that you were connected to the wrong phone number, or you may find you were cut off in midsentence. A whole host of problems increase as you increase the ambient noise in the system.

That is precisely what happens with traumatic brain injury. In a one-to-one situation, the individual with a minor or severe injury will look very similar to you or I. As you increase the amount of stress in the environment, be the stress psychosocial, financial, or physical in any way, shape or form, the individual's performance deteriorates.

Clearly that is one of the major difficulties in terms of diagnosing and treating traumatic brain injury.

Another thing that makes traumatic brain injury unique is that it is not a static entity. When I was in medical school 12 years ago, we were taught that brain cells do not regenerate.

Now we know that they do, albeit at a slow rate. There is a potential for growth and rehabilitation during the entire time postinjury. But, it is clear that the earlier one has rehabilitation, the better the ultimate outcome.

In 1981, less than 8 percent of individuals with traumatic brain injury returned to work. Now with certain types of programs, primarily supported employment, 80 percent can return to competitive employment.

Yet we need to have ongoing supplemental financing for these individuals during the time that they are being rehabilitated. Currently, less than 10 percent of individuals across the United States receive formal rehabilitation due to multiple factors.

In one study, 40 percent of children in emotionally disturbed classes had unrecognized traumatic brain injury. In another study

in a mental health clinic, two-thirds of the patients a history of brain injury.

As you increase comorbidity with other medical or emotional difficulties, the cost also increases. It was estimated in 1980 that $14.4 billion annually was lost from motor vehicle accidents.

This is second only to cancer in terms of national cost. Yet the problem is that there is still no separate recognition under Social Security listings for traumatic brain injury unlike that which exists for Alzheimer's disease or autism.

We are looking at 2 million Americans who have survived TBI. We are getting better at having people survive the injury, but we are increasingly having difficulties in terms of providing them with some quality of life following the injury from which they have been saved.

Evaluation is a critical portion of this. It requires extensive neuropsychological testing often requiring more than 6 hours of evaluation at a crack.

The other issue relates to training. A dozen years ago when I was in medical school, people were not surviving head injury to a great extent. At this time the survival rate is 75 percent. We have learned a lot in terms of air evacuation and stabilization since Vietnam.

But we have not accommodated these individuals to assist them in terms of the rehabilitation efforts that they need.

In closing, I would like to present one brief vignette to illustrate the level of difficulty encountered. It was an item captioned in the paper a year and a half ago concerning a mother who committed suicide following her murdering her head injured teenaged son who had been turned down for Social Security benefits under the current guidelines as listed..

While the end result in this story was perhaps even more tragic than most, denial of benefits is not an uncommon difficulty of individuals with traumatic brain injury. They fall through the cracks of our current listings.

I would hope that today's testimony would lead to a rewriting of these guidelines and permit a separate SSI category for individuals with traumatic brain injury.

[The statement of Gregory O'Shanick follows:]

STATEMENT OF GREGORY O'SHANICK, M.D., NATIONAL HEAD INJURY FOUNDATION

The National Head Injury Foundation (NHIF) would like to express our appreciation to this committee for the opportunity to testify, both orally and with submitted materials regarding our concerns with the present Social Security Listings as they affect people with traumatic brain injury.

Many individuals who have sustained head injury, who are severely impaired, have little difficulty in receiving SSA or SSI benefits. The severe problems that we observe are the barriers that are faced by individuals who have sustained what is referred to as minor traumatic brain injury. There are significant flaws in the current regulations that will not allow the disability program to work for this population. We have been working with the Social Security Disability Administration since 1984 and have made some progress but the primary request that is most significant has not been met. That is, to establish a distinct catagory for traumatic brain injury (TBI). Until that is done, the issues that we are about to outline will not be sufficiently addressed. Another barrier that we face is the lack of knowledge among Social Security Disability Administration personnel and judicators at the state and local levels in TBI, and the access for our people to receive a appropriate evaluations. Combined, all of these obstacles represent tremendous and insurmountable barriers for those individuals struggling to regain an increase level of independence and function.

Traumatic Brain Injury is the major cause of disability of people under age 35 in this country. We recognize the financial impact on society and the economic and emotional burden to families. Denying individuals the financial benefits which will discrease the long-term effects of disability is not cost effective. In 1985 and again in 1988, the National Head Injury Foundation (NHIF) had the opportunity to present significant information either through discussion or in testimony directly to the Social Security Disability Administration. I have taken this opportunity to include statements, both partial and full, made by psychiatrists and neuropsychiatrists who are nationally recognized for thier work with individuals who have sustained traumatic brain injury. These professionals are deeply involved in the work of the National Head Injury Foundation (NHIF). The first inclusion is a statement made by Irwin W. Pollack, M.D., Director, Center for Cognitive Rehabilitation, University of Medicine and Dentistry of New Jersey, Rutgers Medical School, N.J. on December 10, 1985.

> "The major problem with the proposed Social Security recommendation for Traumatic Brain Injury lies in the fact that the impairment caused by brain injury is required to be judged on its equivalency to the listed impairment of some single organ system. While there is a mechanism to consider impairment in multiple systems, this appears to be little more than an afterthought.

The brain's only function is the control and regulation of other organ systems both individually and collectively. While injury to other organs of the body disrupt some or all of the functions of that organ and indirectly of a few other organs with which it interacts, any serious injury to the brain always disturbs the function of more than one organ system some of which interact and others of which function relatively independent of one another. In other words, the effects of brain damage are seen only in the impairment of the function of other organs.

When the damage to the brain is diffuse rather than localized as is the case in most motor vehicle accidents, the function of many organ systems are disrupted. When this occurs even to a modest degree, the integrated activities which are necessary for effective physical, intellectual, and social performance can not be maintained. This is true evn when the functions of the separate organ systems are relatively intact. In this case, the impairment suffered by the whole individual is greater than the sum of the impairments to the several organ systems and therefore cannot reasonably be weighed against impairment of a single organ system or even to a combination of impairments in several organ systems.

In some other cases, a localized injury to a part of the brain which is responsible for high level integrative processes (frontal lobes) leaves the function of all major organ systems completely intact and yet gravely impairs the competence of the individual by destroying his/her ability to plan, set goals, and exercise responsible judgment. The impact of this sort of global impairment can not be evaluated by comparing it to the impairment caused by damage to an organ system or systems."

The following inclusions are statements made by Jonathan M. Silver, M.D., Columbia University College of Physicians and Surgeons, and Stuart C. Yudofsky, M.D., Department of Psychiatry, University of Chicago.

"We propose that traumatic brain injury (TBI) be listed as a separate categorical diagnosis. If, in order to maintain the current framework of the diagnostic listings, this proposal is rejected, we ask that the definitions of Organic Mental Disorders (12.02) be modified so that the symptoms of patients with TBI will be included under this category.

1. Traumatic Brain Injury as a Categorical Diagnosis

TBI is the most common etiology of organic mental disorders. Each year in the United States over 500,000 people suffer traumatic injuries to the brain. A far larger number are afflicted with the chronic sequelae of such injuries. The incidence of brain injuries in the United States is approximately one and one-half times the incidence of schizophrenia. Of the cases of traumatic brain injuries, 30 to 50 percent are associated with moderate to severe brain injury or are fatal; 5 to 10 percent of the survivors have residual neurologic dysfunction. Patients who have "minor" injury also may suffer from prolonged cognitive and psychiatric disability. In this population, the psychosocial and psychological deficits are the major source of disability to the victim and of stress to the families. Because the victims of traumatic brain injury are young, the economic cost is staggeringly high. In 1980, Hartunian estimated that the total economic cost per year for motor vehicle injuries was 14.4 billion dollars, only second to cancer.

Unfortunately, the psychiatric impairments caused by TBI often are unrecognized due to the absence of appropriate education in this area for psychiatrists and other health professionals. Most clinicians lack experience in the treatment and evaluation of these patients, and are therefore unaware of the subtle but disabling symptoms. For example, irritability is often rationalized as the patient's frustration with his situation, and not as a result of specific brain lesions. Thus, the patient does not receive the proper treatment.

A history of significant TBI may precede major psychiatric disorders, but is overlooked or minimized during the psychiatric evaluation. In a study at Columbia University, headed by Dr. Carol Canton, we are examining predictors of homelessness in psychiatric patients. In a preliminary survey of these patients, severe brain injury has been common, and has frequently preceeded the occurence of psychotic symptoms. The detailed history of these patients in their hospital records has frequently omitted documentation of the injuries and/or consideration to its etiologic role for the patients' psychiatric symptoms.

The lack of a categorical diagnosis for TBI impedes the recognition of the syndrome. Recognition of TBI as a specific mental impairment by the Social Security Administration and its inclusion in section 12.00 would result in an increase in the number of professionals who recognize the functional disability from TBI. Prolonged disability would be alleviated after appropriate assessment and treatment.

11. Proposed changes to the criteria for Organic Mental Disorders (12.02)

The Social Security Administration may decide that mental impairments of patients with TBI should be continued to be evaluated under the criteria for organic mental disorders. In our experience, patients with TBI may suffer from disabling emotional symptoms that may not be included under 12.02A. We, therefore, propose that the specific criteria be modified (see enclosure).

Patients with traumatic brain injury may not always be included under the requirements for Organic Mental Disorders. In 12.02A, the diagnosis of Organic Mental Disorders requires the demonstration of "a loss of specific cognitive abilities or affective changes." However, because of the areas of the brain that may be injured, dysfunction of cognition or affect may be minimal.

Because of the vulnerability of the prefrontal and frontal regions of the cortex to injury, specific changes in personality known as the frontal lobe syndrome are common. In the prototypic patient with frontal lobe syndrome, the cognitive functions of the patient are preserved while personality changes abound. These changes include decreased motivation and impaired social judgment. Patients may display uncharacteristic lewdness, inability to appreciate the effects of their behavior or remarks on others, a loss of social graces, a lack of attention to personal appearance and hygiene, and boisterousness. Patients may appear shallow, indifferent, or apathetic, with a global lack of concern for the consequences of their behavior.

Other prominent behavioral traits such as disorderliness, suspiciousness, argumentativeness, isolativeness, disruptiveness and anxiousness become more pronounced with brain injury. Headaches, fatigue, sleep difficulties and memory problems commonly occur.

Post-traumatic psychoses can occur either immediately following brain injury or after a latency of many months of normal functioning. At times, patients with schizophrenic-like symptoms subsequent to brain injury may be indistinguishable from symptoms of the "naturally occurring" disorder. These symptoms may persist despite improvement in cognitive deficits caused by the trauma.

In those patients who suffer brain injury, irritability and aggressiveness are a major source of disability to the victim and of stress to their families. These behaviors persist long after the injury, and may be present despite absence of cognitive and affective change.

Problems with intellectual functioning may be among the most subtle manifestations of brain injury. Changes may occur in the capacity to concentrate, use language, abstract, calculate, reason, remember, and process information. Intellectual changes and ability to attend to tasks, even if not perceptible to others, influence the social rehabilitation of the head-injured patient.

Pre-existing affective illnesses are aggravated by brain injuries. Patients may develop major depressive episodes or manic episodes de novo subsequent to the brain injury. Affective lability, with sudden shifts from tearfulness to laughing is a common result of brain injury.

The emphasis of 12.02A on the loss of cognitive abilities or affective changes implies that the absence of dysfunction of these areas excludes the presence of an organic mental disorder, and thus excludes eligibility of TBI patients for disability.

One example of such a patient (documented on videotape by Dr. Yudofsky) is a middle aged scientist who suffered TBI after his airplane had crashed into the side of a mountain. During the immediate posttrauma period, he had to learn how to read, write and use mathematics. However, he was unable to regain his highly developed ability to perform difficult calculations in his head. Because of his high level of intelligence, this deficit was not detectable on standard neuropsychiatric tests. In fact, he went on to receive a business degree and start his own company. However, he developed severe dyscontrol of rage and violent behavior that resulted in family problems, including the potential for abuse of his children. When he first sought psychiatric treatment for this problem, he was told that he could possibly be helped through several years of intense psychoanalysis to "work through" feelings that stemmed from his childhood. Fortunately, he found a neurologist who was familiar with this condition and successfully treated his agressive outbursts with beta-blocking drugs.

Although "change in personality" is listed (12.01 A1), no mention is given to apathy, a common symptom of frontal lobe injury. Emotional lability (e.g. sudden crying) is confused with outbursts of temper and irritability (12.01 A6). Unless aggressive behavior is listed specifically as a criterion, the clinician will overlook the diagnostic importance of this problem. We have addressed this issue by proposing a specific diagnostic category of "Organic Aggressive Syndrome." Impaired social judgment is another frequent behavior that results from frontal lobe injury. Although it can result in difficulties with social situations and with work, (and is, therefore, covered in 12.02B), the omission from A criteria is

clinically erroneous. Receptive and expressive ideation as revealed through language, such as receptive and expressive aphasias, should be included specifically.

The confirmation of "a specific organic factor judged to be etiologically related to the abnormal mental status" may be through brain imaging techniques or neuropsychological testing. It must be emphasized that these tests may not indicate abnormality despite the presence of severely disabling symptoms that directly resulted from TBI.

Advances in brain imaging have made it easier to document brain damage after traumatic injury. While computerized tomographic (CT) scans detect many types of focal injuries, the shearing injuries to axons cannot be visualized. Magnetic resonance imaging (MRI) is able to detect these types of injuries. However, some lesions may even go undetected by MRI. One example is the married mother of a 2 year old daughter. One winter day, she slipped on the ice and fell on her coccyx and the back of her head. After being unconscious for 20 minutes (a "minor" head injury), she made her way home. During a visit to the emergency room later that day, she was told to take analgesics and rest. Since that time almost two years ago, she has had difficulties in remembering things, gets lost while driving, frequently loses her temper, will cry for no reason, is sensitive to noise, has severe headaches, and has occasional auditory and visual hallucinations. It was not until the second MRI scan that the small lesions on her bilateral temporal lobes were detected.

In another case, a 50 year old man fell down a flight of stairs and did not lose consciousness. However, he was confused and combative for the subsequent six weeks. An initial MRI scan revealed multiple frontal and parietal contusions. After his confusion resolved, a repeat MRI scan was obtained that was normal, with resolution of all contusions. However, a regional cerebral blood flow scan revealed continued abnormalities in the areas of previous contusions. This was consistent with the results of extensive neuropsychological testing.

Neuropsychological test batteries that may take up to six hours to administer can detect the presence of brain injury and the difficulties the patient has in concentrating and remembering. It should be noted that qualified neuropsychologists are not available in all areas of the country, and this type of detailed testing is unavailable to the majority of head injured patients. However, a "subtle" deficit on a test may lead to a profound disability. For example, a mildly impaired ability to abstract will not result in problems at work for a man who works on an assembly line in a factory. However, for a Professor of mathematics, the same deficit (which may be undetectable on neuropsychological

testing) may render him unable to work at his profession. Personality changes may also be incapacitating, even though cognitive functioning is relatively intact. For example, a middle-aged lawyer, after suffering severe head injury to her right frontal and parietal lobe, had only mild cognitive deficits. However, her labile affect, anger and inappropriately lewd language made it impossible for her to find employment.

Traumatic brain injury is a common condition that is underrecognized and undertreated. As a result, the suffering of patients and their families is not addressed and is misunderstood. Patients and families wonder what is wrong, and if they are responsible for the symptoms. As these symptoms become chronic, secondary problems develop, including disability at work and school. Stress increases at home as the family attempts to deal with the behaviors of the injured relative. Many relatives become severely anxious and depressed. Secondary gain can develop, where the patient hangs on to the symptom because of the increased attention from family members. This scenario can be avoided with prompt recognition and treatment of the brain injured patient.

The Social Security Administration needs to provide instruction and training for both clinicians and its reviewers regarding the nature and course of the victim of traumatic brain injury. Because of the prevalence of this disorder, a specific diagnostic category would be of immeasurable help in achieving this goal and promoting recognition of TBI. If an additional category is not made, the specific criteria of Organic Mental Disorders must be broadened to include patients with traumatic brain injury.

Proposed Criteria for Organic Mental Disorders (12.02)

Psychological or behavioral abnormalities associated with a dysfunction of the brain. History and physical examination or laboratory tests demonstrate the presence of a specific organic factor judged to be etiologically related to the abnormal mental state and loss of previously acquired functional abilities. In cases of traumatic brain injury, brain imaging tests and neuropsychological tests may not accurately reflect the degree of impairment.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. The medically documented persistence of at least one of the following changes in behavior, thought process, perception, affect, emotional regulation, consciousness, orientation, memory, impulse control, intelligence, or judgement and insight. Patients with traumatic brain injury may also have significant changes in energy and sleep:

1. Behavioral or personality changes, such as apathy, decreased motivation, lewdness, or disorderliness; or

2. Disordered thought process as evidenced by delusions, paranoid thoughts, or marked loosening of associations; or

3. Hallucinations; or

4. Affective changes as manifested by depressive or manic syndrome; or

5. Changes in emotional regulation as manifested by lability (e.g., sudden crying, inappropriate laughing); or

6. Alterations in consciousness, as manifested by impaired alertness and capacity to attend and to concentrate; or

7. Disorientation to time and place; or

8. Memory impairment, either short-term (inability to learn new information), intermediated, or long-term (inability to remember information that was known sometime in the past); or

9. Impaired impulse control, especially uncontrolled outbursts of violent behavior, explosive temper, and irritability; or

10. Loss of measured intellectual ability of at least 15 I.Q. points from premorbid levels or overall impairment index clearly within the severely impaired range on neuropsychological testing. Loss of high level cognition, such as ability to abstract and to process information, may occur despite test results within the normal range; or

11. Impaired judgement in home, work, or social situations, or lack of insight into degree of impairment.

B. Criteria unchanged.

Mr. ANDREWS [presiding]. Thank you.
Ms. Little.

STATEMENT OF JEAN LITTLE, CHAIRPERSON, SSI, SSDI COMMITTEE, NEW YORK STATE ALLIANCE FOR THE MENTALLY ILL

Ms. LITTLE. My name is Jean Little. I am a parent of two SSI children. I think our family has received SSI ever since it has been in existence. David was born with cerebral palsy, and is now 24. When he was about 8, someone told me he was eligible. I was delighted to hear it. I was a single mother with five children. My ex-husband paid child support and I worked, but we didn't quite make it.

I was very glad to get some help from the program. In 1976, due I think, to drug abuse, at the age of 14, my third oldest son, Timothy became mentally ill and spent the next 13 years in and out of mental hospitals. For the last 5 years, from age 21 to 26 he received a check for SSI in one amount or another, depending on whether he lived with the family or on his own. Tim died April 3, 1989 of a broken aorta due, I think, to cocaine. No autopsy report yet.

So, I know quite a bit about how the system works. As a result of my son's being mentally ill, I joined the National Alliance for the Mentally Ill at the local scene. I became a member of the Mid-Hudson Chapter, and later a member of the New York State Alliance.

We all work together. As a result of my frustration with the SSI redtape, you might say, I decided to talk to others about it in my New York Alliance group. I could not explain it to them, it was so complicated, so I wrote an article. I will now read what I have written for today for formal testimony.

My name is Jean Little, and I am Chair of the SSI Committee of the New York Alliance for the Mentally Ill, a State organization aligned with the National Alliance for the Mentally Ill. As chairperson, I conducted a survey of our membership on a number of issues pertaining to the SSI laws.

Leading up to that, I wrote an article entitled, "SSI Laws Need Changing to Allow Families to Provide for Disabled Relatives After Death." I would quote from that article and refer you to all of it in pages 2 and 3 and 3(a) of my submitted testimony.

Now families are contemplating what will happen to their chronically ill sons and daughters after they are gone. We hear about the homeless mentally ill on our city streets and wonder how we can prevent this from happening to our children, who will no longer be children when we leave them, but middle-aged adults who depended on us most of their lives for care and support.

The last page of this quoted article is a graph which explains how I would propose that private money work together with SSI and SSDI money. I anticipated Congressman Steve Bartlett's and Robert Matsui's bill, H.R. 71, by more than a year's time. Their bill, which I am so pleased is sponsored by a Democrat and Republican, is entitled "The Independent Living Contributions Trust of 1989."

I am here to support this particular bill as helpful above all of them, though I support the other bills also and wish to thank Congressmen Edward Roybal, George Miller and Thomas Downey for sponsoring H.R. 866, H.R. 867 and H.R. 868.

The questionnaire I sent out and reported on last October also addresses issues that are before you now. So I traveled from New York to share this information with you.

The complete report is two pages long in this testimony, and is pages 4 and 5. Some of the questions and answers refer to New York State laws regarding Medicaid, SSI and trust funds. The questions of special interest to you on this subcommittee are 1, 2, 6, 7, and 8. I include the entire report, and I have checked off the questions, 1, 2, 6, 7 and 8.

I will be attending the National Alliance of Mentally Ill conference over the July 4th weekend, and I will be a panel member in a workshop entitled, "SSI/SSDI: Changing the System of Enforced Poverty," which I personally suggested. I will bring to this workshop what I am learning today here about SSI legislation and what the membership of families all over the United States can do to help pass the laws now before you.

Thank you for this opportunity to be here. If there are 10 more minutes available, I would like to have the opportunity to read the questions pertinent in the record.

Mr. ANDREWS. Please go ahead, Ms. Little.

Ms. LITTLE. Question 1: The present laws, Federal and State, allow a disabled person to have $1,900 in the bank at any given time and still be eligible for benefits—this was last year. I believe the amount was raised to $2,000 in January of this year.

"Do you think this is enough for a handicapped person to have who wants to establish his or her own independent living (apartment)?"

One hundred sixty-six people said no, nine said yes, and two did not answer.

Question 2: If you answered "no," what would you suggest as a ceiling?

The answers given ranged from $2,500 to $5,000. About half the answers were from $2,500 to $4,000; the other half stated $5,000. Clearly, all agree that the present ceiling is too low.

Question 6: Do you know of anyone who is living independently on the $425 total a month that a handicapped person could receive in New York in 1988?

The answers were a resounding no, with only two exceptions. One astute gentleman said that Mexicans do not see that much money in a month. We would add that neither do the unemployed, homeless people of our American cities. But we are not aiming for life as it is lived in the slums of Mexico or on our city streets.

The question is, Do you know of anybody who can rent a place to live, feed and clothe himself on the maximum $425 an SSI recipient is entitled to in the State of New York? Most said a simple "no." Others said it was "impossible in this area with rents so high." Those comments were listed under the next item: "Please give details if your answer is yes." Generally, this was left blank.

Question 7: Would you favor laws that would allow a disabled person to have a trust fund that generates support money that

would supplement SSI monthly payments? Yes replies were 171, no were 2, and 6 did not answer. Comments on this question were few.

But one parent asked: "How could we guarantee the trustworthiness of those in charge of the trust?" That is a bridge we can cross when we get a law to allow us to do what we should do as parents, provide a safety net for our disabled sons and daughters. I think the Alliance for the Mentally Ill can help us solve that one in time.

Question 8: What ceiling on monthly income would you suggest be the cut-off point when SSI payments are no longer needed? My suggestion for needed income per person for complete independence, including medical insurance payments into a group plan sponsored by a nonprofit agency, is $850 per month. The need for private insurance is because so many doctors refuse to accept Medicaid patients.

Answers were: 134 for $850 to $1,000, 24 above that figure, 21 no answer. The one person who answered $650 was a patient/client whose mother urged him to fill out the questionnaire. To him, that would represent an increase of $225 a month over his present check, and would cover basic needs. But it would not cover private insurance for medical care, which is expensive.

Thank you for allowing me to read this part of enclosed testimony.

Mr. ANDREWS. Thank you.

[The statement of Ms. Jean Little follows:]

TESTIMONY for Sub Committee on Human Resources

BY: Jean Little, Chair, SSI Committee, New York State AMI
(Alliance for the Mentally Ill)

Honorable Members of the House Congressional Ways and Means Sub Committee on Human Resources:

My name is Jean Little and I am Chair of the SSI Committee of the New York Alliance for the Mentally, a state organization affiliated with the National Alliance for the Mentally Ill.

As Chairperson of the SSI/SSDI Committee of New York State AMI I conducted a survey last year of our membership on a number of issues pertaining to SSI laws. Leading up to that survey I had written an article entitled: SSI LAWS NEED CHANGING TO ENABLE FAMILIES TO PROVIDE FOR DISABLED RELATIVES AFTER DEATH. I would like to quote a paragraph from this article, and refer you to read all of it in the testimony attached, pages 2,3 & 3A.

> Now families are contemplating what will happen to their chronically ill sons and daughters when they are gone. We read and hear about the "homeless mentally ill" on our city streets and wonder how we can prevent this from happening to our children, who will no longer be children when we leave them but middle aged adults who have been dependent upon us most of their adult lives for care and support.*
> ...

(*ABOUT 40% OF DEINSTITUTIONALIZED PATIENTS LIVE AT HOME WITH PARENTS)

This article goes on to refer to the asset limit and its detrimental effect on our (families') ability to provide trust funds for our children. The last page of this article is a graft which explains how I would propose that private family money work together with SSI/SSDI money to provide adequate income for recipients. I anticipated Congressman Steve Bartlett's (R-TX) and Robert Matsui 's (D-CA) bill: H.R. 71 by more than a year's time. Their bill, which I am so pleased is sponsored by both a Democrat and a Republican, is entitled: The Independent Living Trusts and Contributions Act of 1989." I am here especially to support this particular bill as helpful above all of them, though I support the other bills also and wish to thank Congressman Edward Roybal, George Miller and Thomas Downey (D-NY) for sponsoring H.R. 866, 867 and 868.

The Questionnaire that I sent out last summer and reported on last October to our New York membership also addresses issues that are before you now, and so I traveled from New York to share this information with you. The complete Report is 2 pages long in this testimony and is pages 4 & 5. Some of the questions and answers refer to New York State laws regarding medicaid, SSI and trust funds. The questions of special interest to you on this subcommittee are Questions 1, 2, 6, 7 & 8. I include the entire report on pages 4 and 5 of this testimony, and I've checked off questions 1, 2, 6, 7 and 8.

I have two minutes left so I would like to read these particular questions and their answers to you.

> (Here I will read directly from pages 4 and 5 of this submitted testimony)

I will be attending the National Alliance for the Mentally Ill conference in Cincinatti, Ohio over the July 4th weekend, and will be a panel member of a workshop entitled SSI/SSDI Changing a System of Enforced Poverty, which my work inspired (and I personally suggested). I will bring to that workshop what I am learning here today about SSI legislation and what the membership of families from all over these United States can do to help pass the bills now before you.

Thank you for this opportunity to be heard. Be assured of the support of all the families of disabled persons.

SSI LAWS NEED CHANGING TO ENABLE FAMILIES TO PROVIDE FOR DISABLED RELATIVES AFTER DEATH
by Jean Little

The "deinstitutionalization" of the mentally ill has been going on now for over twenty years. Many families have taken up the entire responsibility of the care of their ill family members since there are no alternate facilities available in their communities to do so. The families have struggled along with the new system, some of them failing to cope, others rising to heroic stature - but it has been grossly unfair to them. With no other illness is the family expected to carry such a burden.

Now families are contemplating what will happen to their chronically ill sons and daughters when they are gone. We read and hear about the "homeless mentallyill on our city streets" and wonder how we can prevent this from happening to our children, who will no longer be children when we leave them but middle aged adults who have been dependent upon us most of their adult lives for care and support, emotionally and financially. The lawyers who have come to our meetings of parent support groups to help us solve this dilemma have told us that we should do nothing for our disabled unless we can do everything for them. This is because the disabled have to be so poor to receive government help (the safety net?) that to leave them even $2,000 in a trust fund would disqualify them for any government help (SSI and medicaid). Therefore, if we can't leave them enough to cover ALL their expenses, plus any medical expenses they might incur in the future, we should DISINHERIT them, leaving them to subsist on the $411 maximum amount of a monthly SSI check, plus food stamps, medicaid and hopefully, a rent subsidy. ($340. from federal government, $71.91 from NYState)

This all or nothing at all position we are in is unfair to us, to our disabled children, and the taxpayers. A much more equitable solution would be to allow us to supplement our children's government SSI check to the best ability we can, up to an amount that would at least equal the government subsidies they are entitled to, approximately worth $250 a month not including medicaid, which is worth an additional $150 a month in insurance premiums. The big difference would be that we would KNOW the trust fund is in place to take our place, while we cannot be sure that the government rent subsidy program will continue or that our chronically ill family members will know how to avail themselves of it if it is in place. In addition, there is a two-year wait for a person applying for a Section 8 rent voucher. What does a mentally ill person who cannot work and must rely solely on government help do in the meantime?

But the solution is not even that simple. For on top of present laws that make anyone ineligible for government help if he or she has assets over $1,800, there is another law that says that hospitals can enter trust funds for repayment of hospital bills. That is, either state hospitals or private ones not only can, but in the case of the state, are obliged to do so to recover funds spent on behalf of the patient. Therefore, we need another change in state laws to protect trust funds that are the sole means of support of disabled persons (solely or with government SSI help). I refer here to attached graft showing how income from trust funds and government checks would work together to preivde an adequate income

for living in this expensive society. This graft does not include money needed for payment of private insurance, which would raise the ceiling to $801 dollars a month.

Of course, there are plenty of people who are physically or mentally handicapped whose family cannot leave them an inheritance in a trust fund. The full range of government programs would still be needed for them. But in the end, the combination of help from families who can provide it, and government programs for those who haven't this kind of help, would result in far more of our chronically ill citizens being properly cared for than is the case now, and hopefully the "homeless" situation of many of them could be entirely avoided.

It is hypocritical of us as a society to wring our hands over the "homeless mentally ill" and not do something to correct it when it can easily be done. According to the "either all or nothing at all" choice, most families under present laws will have to choose to leave nothing at all behind for the care of their disabled sons and daughters, casting the whole burden upon the taxpaying public. We are not doing such a great job with the burden we now have. It will be awesome ten or twenty years down the road. I therefore certainly would welcome hearing from any of our

lawmakers who would be willing to sponsor such legislation. The Congress must deal with the SSI laws. The individual states must deal with the invading of trust laws. There should be great public support for my suggested changes, and to help rally that support I expect a lot of help from other families in the National Alliance for the Mentally Ill, whose national offices are in Washington, D.C. and who have the utmost interest in seeing that the laws on our books now are made more equitable.

I am hopeful of hearing from any person or organization who wishes to express support for these needed changes in the law, and any lawmaker who wishes to sponsor such legislation as will be needed to make the changes. I will contact Senator Harkin, Chair of the Senate Labor and Human Resources Subcommittee on the Handicapped directly.

But I truly hope there will be many others who will want to join this effort. The "journey of a thousand miles begins with one step." This is the first step - presenting the problem. It will take many others, each taking a necessary step, to cover the miles on this road to justice. Contact Senator Harkin regarding your support for these measures, and your state legislators. And let me know, please, that you have done it. Just write to: Mother of Two, Hyde Park Estates, 4G, Hyde Park, NY 12538. Permission granted to copy in whole or in part any portion of the above with or without acknowledgement to its author, Jean Little, Mother of Two.

Jean Little
11-27-87

I propose that an amount equalling the present government subsidies (about $250 a month if you only count rent and food stamp subsidies)* be allowed as the maximum amount a handicapped person can receive from a family trust and still receive all of his/her SSI income, which is $411 a month (in NY) at present, making $651 the ceiling for monthly income.

After the $651 ceiling has been reached, government SSI checks would decline in amount as trust money monthly increased.

The easiest way to present this is in graft form. Please refer to graft on this page.

The point at which no government check will be needed is when the income from the trust reaches the $651 level, and beyond.

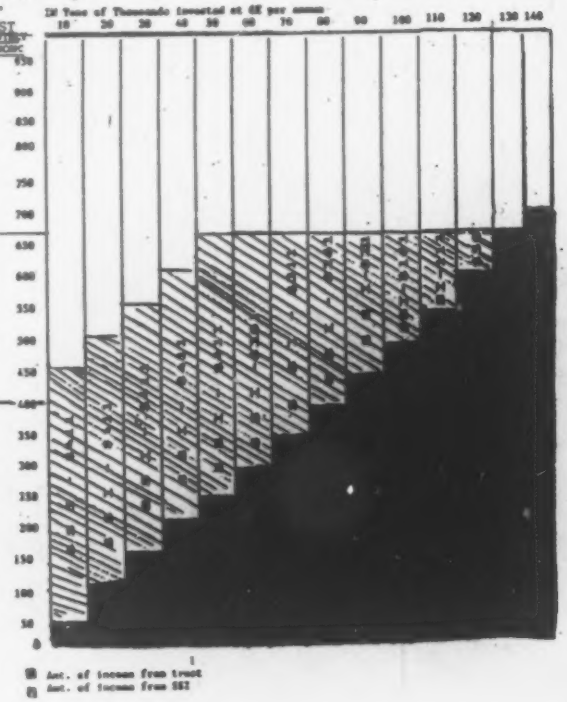
It follows, therefore, that all principal in the trust needed to generate this monthly income, from $10,000 up to $130,000 needs to be inviolate from liability for hospital costs.

* We might want to consider adding to the amount of $250 a month subsidy allowed an additional amount to cover private insurance coverage. Certainly it would save the government money, but more important, it would assure our handicapped relatives of better medical care. It is, or should be, common knowledge that most doctors today will not accept medicaid patients. So what good is a medicaid card if doctors will not honor it? Far better if families could provide life-time coverage for their sons and daughters. Group rates could be gotten if this were done through a national organization like the National Alliance for the Mentally Ill.

This, of course, would be strictly voluntary on the families' part.

PROPOSAL FOR FAMILY SUPPLEMENT TO SSI INCOME THROUGH A TRUST

A. Proposed level of income (SSI contributions and Family Trust Income -$651)
B. Present Maximum level of SSI Income for single person living alone ($411)



Written October, 1988

REPORT ON "QUESTIONNAIRE ON SSI LAWS" FOR NEW YORK STATE AMI BY THE COMMITTEE FOR SSI, JEAN LITTLE, CHAIRPERSON

The SSI Committee of New York State Alliance for the Mentally Ill has received to date 179 replies to its questionnaire. This is a sufficient sampling of opinion to be quite sure on the areas we all agree on. The breakdown of answers will be given below. Following that will be comments and suggestions also included in the returned questionnaires.

Question 1:

The present laws (federal and state) allow a disabled person to have $1900 in the bank at any given time and still be eligible for benefits.

Do you think this is enough for a handicapped person to have who wants to establish his/her own independent living (apartment)? 166 No, 9 Yes, 4 NA.

Question 2:

If you answered "no," what would you suggest as a ceiling?

The answers given ranged from $2,500 to $5,000. About half the answers were from $2,500 to $4,000; the other half stated $5,000. About 15 replies suggested a figure OVER $5,000. Clearly all agree that the present ceiling is too low.

Question 3, 4 and 5 brought nearly total agreement on answers.

Question 3:

Do you think that a severely handicapped person needing the aid of another person should receive $50 less a month for living with and sharing meals with a helping person? 177 No, 1 Yes, 1 NA.

Question 4:

Do you think that two handicapped persons should each receive $50 less a month for living together and trying to help each other with shopping, cooking? 175 No, 2 Yes, 2 NA.

Question 5:

Do you think such laws (New York State laws) are discriminatory against the most severely handicapped persons who are trying to live outside institutions? 176 Yes, 1 No, 2 NA.

To Question 6: Do you know of anyone who is living independently on the $425 * total a month that a handicapped person can receive? The answers were a resounding "NO," with only two exceptions. One astute gentleman said that Mexicans do not see that much money in a month." We would add that neither do the unemployed, homeless people of our American cities. But we are not aiming for life as it is lived in lthe slums of Mexico or on our city streets. The question is, do you

*On Jan. 1, 1989 this amount was raised to $445 due to Cost of Living increase.

know of anybody who can rent a place to live, feed and clothe himself on the maximum $425 an SSI recipient is entitled to in the State of New York? Most said a simple "No." Others said it was "impossible in this area with rents so high." Those comments were listed under the next item: Please give details if your answer is yes. Generally this was left blank.

Question 7. Would you favor laws that would allow a disabled person to have a trust fund that generates support money that would supplement SSI monthly payments? 171 Yes 2 No 6 NA. Comments on this question were few. But one parent asked: "How could we guarantee the trustworthiness of those in charge of the trust?" That is a bridge we can cross when we get a law to allow us to do what we should do as parents, provide a safety net for our disabled sons and daughters. I think the Alliance for the mentally Ill can help us solve that one in time.

Question 8. What ceiling on monthly income would you suggest be the cut off point when SSI payments are no longer needed? (Our suggestion for needed income per person for complete independence, including medical insurance payments into a group plan sponsored by a non-profit agency, is $850 per month). Answers were: 134 $850 to $1,000. 24 ABOVE that figure. 21 No Ans. The one person who answered $650 was a patient/client whose monther urged him to fill out the questionnaire. To him that would represent an increase of $225 a month over his present check and would cover basic needs. But it would not cover private insurance for medical care, which is expensive.

In our questionnaire I stressed the need for private insurance for medical care because it is so difficult to find doctors that will treat medicaid patients. Wondering if this was commonplace and not just local, questions were asked in the final part of the questionnaire about medical treatment for SSI recipients. Before we get to that, the tallys on questions 9 and 10.

Question 9. Should a trust that generates support for a handicapped person (with or without SSI payments) be held to be free from invasion by the state or private hospitals for payment of hospital bills? 177 Yes 1 No. 1 NA. It is our task to get our lawmakers (federal and state) to address this problem so that we can approach the task of setting up trust funds with greater confidence and zeal. As it stands now, we cannot.

Question 10: Should SSI recipients between the ages of 21 and 65 be covered for state psychiatric center care by medicaid - thus eliminating the accrual of hugh dept by SSI recipients? Answers: 164 Yes, 1 No, 14 NA

As the law stands now, the federal government, which contributes money to medicaid, a state program, forbids the use of federal money to be used to pay state hospital expenses for medicaid recipients between ages of 21 and 65. The State does not refuse indigent people hospitalization, but the patient does incur a financial liability to the State - and if he or she inherits money or a trust, the State can take its legal course in claiming money for prior (or current) hospitalizations. This must change if trust funds left for the care of disabled persons are to be secure for that purpose.

The three final questions and comments relate to medical care for SSI recipients.

Question 11. Is your relative on SSI having a hard time finding a doctor to take care of his/her medical needs? 105 Yes, 45 No 29 NA
Many who answered "no" qualified this by saying: My son is in the hospital right now, or, "My son attends a clinic," or, "We are paying for private doctor (which translates into a "Yes" to the question) or, "Our insurance pays for medical needs." Generally, it can be stated that SSI recipients depending on medicaid do have trouble finding doctors, psychiatrists and dentists that will treat them. Furthermore, the treatment in clinics is not satisfactory to many respondents. Doctors see patients "once a month" for five minutes, I was told by more than one person, (referring to psychiatric clinics.)

Question 12. Do you think that medical doctors and psychiatrists should be reimbursed by the State at the "going rate" for their regular patients when they treat medicaid patients? 136 Yes, 23 No. Other responses included paying doctors a higher rate than they now receive but not as high as the "going rate" for their services. Those that did not think the rates should be raised most often had other suggestions for "getting all doctors and psychiatrists to stop their discriminating against medicaid patients."

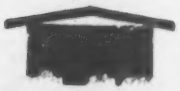
Question 13. Do you advocate this (paying doctors the "going" rate) as a way of getting all doctors and psychiatrists to stop their discriminating against medicaid patients? 136 Yes, 20 No, and 23 NA.

Question 14: Do you have any other suggestions for solving the problem of doctors refusing care and treatment to medicaid patients? was an essay type question. The most frequent answer given was: national health care, or national health insurance or even "socialized medicine, like they have in England."

The second most popular suggestion was for "each doctor to treat a certain percentage of the medicaid patients."

A third suggestion was to: decrease paperwork doctors have to be bothered with when they treat medicaid patients, and faster payment by the State.

"Education and Advocacy with local medical and dental associations" was the suggestion of one individual and makes a good deal of sense. Done on the local level by our local groups it could have an effect that might be astounding. In a way , this person read my mind. Because I do hope that this report will be an education and a means of advocacy for all of the above by all of us.



FRIENDSHIP HOUSE
1746 W. Division • Chicago, Illinois 60622 • (312) 227-5065

March 27, 1989

Dear Friends,

Hello again from all of us at Friendship House. I apologize for the lack of a letter lately. We have a new addition with us. His name is Scott Cihlar, and I have been helping him to move out and in. We do not know how long Scott will be withus, but while he is, he is a big help.

We are having problems with our continuing situation with the men's medical affairs. We send them to St. Mary's with a nice letter, and they come back with a nice prescription to be filled. We have men coming to us every day who want to stop drinking - nowhere to send them. They go to Haymarket House, stay overnight, and come out the next morning to nowhere, and the same problem. Our local warming center at the church has closed for the spring and summer. It is still quite cold out there, and our men have nowhere to go. It is difficult to find a place to lie down outside without being bothered by someone - and you had better hope it is the police who are bothering you.

I handle the personal finances for one of the men here, who is on S.S.digability. He has been declared unable to handle his own money. I couldn't understand why until I discovered that he didn't know what order the months come in. It isn't because he never knew, it is because he's badly scrambled. He doesn't know who the president is. We have many people who cannot permit anyone to touch them. Some can't stand anyone even being near them. We have one man who thinks that he is John the Baptist. He also thinks I murdered his family. You may have read about Connie who stays at O'Hare. He saved the life of a little girl there, was given $10 by a priest, and some teen agers promptly took it from him. Just that night I had given Connie a special bath for lice, and gave him all new clothes. The next day, Connie fell off the L platform right over here at Ashland Ave. He lost one leg, broke the other leg, and one arm. Gentle, sweet, simple Connie. So, you see, we deal with many problems here. Alcoholism is only one of them. Many of our people do not even drink or use drugs.

As a note, we could really use some good, heavy rubber crutch tips. Several of our men badly need them. Also, please keep coming with the jackets, shirts and pants. Another thing we are completely out of is socks. Thanks for your support so far.

Until next time, God bless and keep you.

In the service of the Lord,

Phil

Phil
For Pax and all

House Bill H.R. 71: Providing for family supplements to SSI

The "Independent Living Trusts and Contributions Act of 1989" was introduced January 3 by Rep. Steve Bartlett (R-TX) and Robert Matsui (D-CA). This bill will change present law regarding Social Security Supplemental Security Income (SSI) to allow parents, families, and others to financially and otherwise assist individuals who have disabilities without jeopardizing the person's SSI and Medicaid eligibility or benefits.

Currently, SSI and Medicaid benefits can be adversely affected when an individual receives other assistance, cash or in-kind, from family members or others. This has caused many families to refrain from providing extra help to an SSI recipient with disabilities or to disinherit such an individual because of the difficulty and complexity of ensuring that the individual does not lose needed support. Contributions or clothing or cash to assist with housing needs result in a reduction of SSI benefit amounts or may jeopardize basic eligibility for SSI and Medicaid.

The problems of making acceptable contributions to an individual are exacerbated when parents are making long-range estate plans. Certain arrangements through trusts or direct inheritance by a person with disabilities can threaten eligibility for the basic supports on which many people must rely.

The "Independent Living Trusts and Contributions Act of 1989" would provide that certain contributions would not adversely affect basic SSI and Medicaid eligibility and benefits. These allowable contributions could be for social services, vocational rehabilitation, private medical coverage, educational services, personal assistance or attendant care services, clothing, or subsidies for rent, mortgage payments, or home maintenance. Under H.R. 71, these services or subsidies could be provided either directly or through trust arrangements. A $7,200 a year cap would be placed on allowable housing contributions under the bill.

H.R. 71 does not provide for new federal benefits or call for the expenditures of more tax dollars. It would simply expand and clarify those areas in which private citizens could supplement the livelihood of people who are dependent on SSI and Medicaid, without jepardizing those very sources of support.

A similar bill was introduced late in the last Congress by Representatives Bartlett and Matsui. No Senate bill has yet been introduced.

TO AMI MEMBERS: WRITE YOUR CONGRESSMAN IN SUPPORT OF THIS IMPORTANT BILL!

—A UNITED WAY PARTICIPATING AGENCY—

THE PIONEER
AMI OF DANE COUNTY NEWSLETTER

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Family Ties Report

Family Ties, the statewide publication of Wisconsin Family Ties, and the Child and Adolescent Service System Program of the Wisconsin Department of Health and Social Services, contains much solid information in its Spring 1989 issue. We have room here to quote only part of an article entitled, *"Should Parents Have a Voice in Court?"* by Joel Ungrodt, Advocacy Specialist, Wisconsin Coalition for Advocacy.

The parents of a child with a severe emotional disorder had been led, out of desperation, to file a CHIPS (Children in need of Protection and Services) petition giving the juvenile court jurisdiction over their child. In so doing, they hope to get services for the child and, in some cases, for the rest of the family, which they have otherwise been unable to secure.

However, as the courts gain jurisdiction, the parents relinquish some of their ability to influence significant decisions about the child's life. Parents' access to information gathered by social services is limited. When court hearings are held, parents, who are among the best sources of information for the child's needs, may be excluded from the process...

The Dane County group, knowing they are not alone in their frustration, thought perhaps other chapters of WFT might want to discuss the prospect of amending Wisconsin Statute, Chapter 48, the Children's Code, to require that parents have an opportunity to be hard at various points during the process, including court hearings at which significant decisions and rulings are made about their children.

If you or your group are interested, contact Maggie Mezera at Wisconsin

Mr. ANDREWS. Mr. Moore.

STATEMENT OF RALPH J. MOORE, JR., MEMBER, GOVERNMENTAL AFFAIRS COMMITTEE, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

Mr. RALPH MOORE. On behalf of the Association for Retarded Citizens of the United States, ARC, I want to thank the Ways and Means Committee's Subcommittee on Human Resources for this opportunity to testify regarding the supplemental security income program and changes needed in the program to help improve the lives of persons with disabilities.

I also happen to be the parent of a 25-year-old daughter who is mentally retarded.

The ARC is the largest voluntary organization in the United States devoted to securing the rights of, and effective services for, the approximately 6 million citizens with mental retardation in this Nation. Its national membership numbers over 160,000 people, more than half of whom are parents of children and adults with mental retardation and includes people who are mentally retarded themselves. The ARC has approximately 1,300 State and local chapters throughout the country. Since its founding in 1950, the ARC has participated actively in the formulation of public policy with respect to the rights of, and services for, citizens with mental retardation, including public policy concerning the supplemental security income and the Social Security disability insurance programs.

I will highlight the several bills. I want to thank Representative Matsui for the work he and his staff have done.

First, I would like to invite the committee's close attention to H.R. 71, the Independent Living Trusts and Contributions Act. This bill was discussed in Mr. Bartlett's written statement, and also in our testimony. Its purpose is to clarify and codify the current administrations policy on trusts and other sources to an SSI beneficiary. This would alleviate difficult problems families face in planning for the future with members of the family with disability.

I urge you to work with the sponsors to achieve passage of this legislation.

I would like to highlight some sections of other bills which are critical to make SSI more accessible for children and others who are disabled. We join with the others who propose changes in the definition of disability for children, dealt with in section 2 of H.R. 868. These are needed to ensure that children with severe disabilities who should be eligible are properly identified and given benefits as early as possible.

You folks in Congress are aware of the problems with delays in needed services for children. A family which has very little income and resources needs all available assistance. Many of these costs, and I could list a number of them, are not covered by Medicaid and must be met in order for the family to meet the needs of the child.

It is inexcusable to deny basic support services for children during the critical early years. H.R. 868 would do several things. First, it will ensure that the Social Security Administration will

consider the child's functional limitations in determining whether a child meets the disability listings.

Second, it calls for presumptive disability for children under age 4 with a congenital or genetic disability until he meets the age where he could be more accurately tested.

It would require the immediate publication of proposed rulemaking for revision of the childhood mental disability listings. A draft listing prepared by the SSA supplemental impairments listing group has gone unpublished for over 3 years, and it is time to revise those listings.

H.R. 877, as other witnesses have pointed out, deals with several particular issues. I would like to highlight two.

Currently, people who first become entitled to title II disability benefits as adults disabled during childhood after July 1, 1987, are deemed to be eligible for SSI benefits. This would extend the date back to 1981. For these people, Medicaid may be critical in paying for long-term care services.

In addition, section 303 would establish a mechanism to establish continued coverage for people who would be Medicaid eligible, as described, who presently encounter serious difficulties in the transition process due to administrative delays.

The committee will not receive a great deal of testimony on these two issues, I suspect, but they are important and we urge you to pass them.

Finally, I will mention a bill with which the committee shares jurisdiction with the Subcommittee on Health, and the Subcommittee on Social Security, that is, H.R. 8, sponsored by Mr. Bartlett and 177 other Members.

The bill would apply a work incentive scheme that is based on the highly successful section 1619 program for persons on SSI and apply that to people who are eligible for SSDI and, for the reasons stated by several witnesses, we strongly support passage of that bill.

I would like to thank the chairman and the subcommittee for this opportunity to testify.

Mr. ANDREWS. Thank you.

[The statement of Ralph J. Moore, Jr., follows:]

STATEMENT OF RALPH J. MOORE, JR., ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

On behalf of the Association for Retarded Citizens of the United States (ARC), I want to thank the Ways and Means Committee's Subcommittee on Human Resources for this opportunity to testify regarding the Supplemental Security Income (SSI) program and changes needed in the program to help improve the lives of persons with disabilities.

The ARC is the largest voluntary organization in the United States devoted to securing the rights of, and effective services for, the approximately six million citizens with mental retardation in this nation. Its national membership numbers over 160,000 people, more than half of whom are parents of children and adults with mental retardation and includes people who are mentally retarded themselves. The ARC has approximately 1,300 state and local chapters throughout the country. Since its founding in 1950, the ARC has participated actively in the formulation of public policy with respect to the rights of, and services for, citizens with mental retardation, including public policy concerning the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs.

As of June, 1988, people with mental retardation made up almost 25 percent of the adults of working age (18-64) with disabilities on SSI. There is reason to believe that another 10-15 percent of SSI recipients have been disabled since childhood. People with mental retardation, along with persons with other mental disorders, constituted over 64 percent of the persons who were using the Section 1619(a) work incentive provisions and over 53 percent of the persons who were using the Section 1619(b) provisions. The response to the Section 1619 amendments since 1987 has been most gratifying to us and to SSA and is a credit to its supporters in the House.

These SSI beneficiaries are dependent upon SSI and Medicaid for many of their basic needs such as food, shelter, clothing, and medical care. Because of the importance of SSI and Medicaid benefits, it is necessary for Congress to continually reexamine the program and to make improvements and changes necessary to fulfill the intent of the program and to remove unintended and unnecessary obstacles which face many current or potential beneficiaries.

The ARC is pleased to see the introduction of five bills which, if enacted, would go a long way toward making necessary improvements in the SSI program:

- H.R. 360 - "SSI Asset Reform Act of 1989"
- H.R. 361 - "SSI Benefit Level Reform Act of 1989"
- H.R. 866 - "SSI Benefit Improvement Amendments of 1989"
- H.R. 867 - "SSI Technical Amendments of 1989"
- H.R. 868 - "SSI Disabled Children Act of 1989"

Because these bills are designed to resolve a number of problem areas which have been identified in the SSI program, our testimony will highlight some of the most important provisions of the bills. There are also two additional bills which we would like to call the Committee's attention to and which will be addressed first. They are H.R. 71, the "Independent Living Trusts and Contributions Act of 1989" and H.R. 8, the "Social Security Work Incentives Act of 1989." The ARC strongly supports each of these measures and urges the Subcommittee on Human Resources to carefully consider the merits and importance of each of these bills

and to act expeditiously in moving these bills toward House passage this year.

"Independent Living Trusts and Contributions Act of 1989", H.R. 71

Parents and families who wish to make contributions to an individual with disabilities, particularly parents trying to plan for the future of their child with disabilities, must be always concerned that such contributions do not jeopardize eligibility for or the amount of benefits under the Supplemental Security Income (SSI) program for persons who are SSI eligible. These concerns are present regardless of whether the contribution is made directly, through a trust arrangement, or by a will. Representative Steve Bartlett (R-TX) has introduced H.R. 71, the "Independent Living Trusts and Contributions Act of 1989," along with Representative Robert Matsui (D-CA), to address these issues.

Under H.R. 71, contributions to an SSI beneficiary, from family members or others, whether directly or through trust arrangements, would not be counted as income for purposes of eligibility or benefit computation if the contributions are made for the purposes of: social services, vocational rehabilitation, private medical coverage, educational services, personal assistance or attendant care services, clothing, or subsidies for housing such as rent, mortgage payments, or maintenance. The bill does not increase federal benefit payments, rather it allows private dollars to supplement the SSI supports on which the individual with disabilities must rely.

Cost considerations resulting from interpretations of some of the provisions of H.R. 71 have triggered a reexamination, which is underway, of the language of the bill. In addition, the Social Security Administration (SSA) reports that many of the goals of the bill can already be achieved through use of existing regulations and policies. Redrafting will focus on eliminating the cost problems by ensuring that current SSA policy is clarified and added to the statutory language so that parents, families, and others may make contributions and plans with a clear understanding of the effect on an individual's benefits.

We urge the Committee to consider the provisions of the bill when redrafted and to work for passage this year. To establish current administrative policy in statutory language should be cost neutral and would be an important step in assisting families in planning for the future welfare of their family members with disabilities.

"Social Security Work Incentives Act of 1989", H.R. 8

Currently under Title II of the Social Security Act, people who are receiving survivors benefits or Social Security Disability Insurance (SSDI) benefits on the basis of meeting the Social Security criteria for disability, cannot remain eligible for cash benefits and Medicare if they earn more than the substantial gainful activity (SGA) level, which is currently $300 a month. The Title II program does not yet recognize that individuals with severe disabilities may be able to work despite their disability and yet still need continued support, particularly medical coverage.

The "Social Security Work Incentives Act of 1989," sponsored by Representative Steve Bartlett (R-TX) and 177 co-sponsors, would create a work incentive provision in Title II of the Social Security Act which will allow SSDI beneficiaries to earn above the SGA level and still retain reduced cash benefits and access to Medicare. The

provisions are modeled along the lines of the work incentive provisions of Section 1619, currently available to Supplemental Security Income (SSI) recipients under Title XVI. While the definition of disability is the same for both Title II and Title XVI, such work incentive provisions are not currently available to Title II beneficiaries. Again, revisions are being drafted to address cost concerns in the bill. One of the revisions will limit the work incentive provisions to those Title II beneficiaries who are adults disabled during childhood. A demonstration project would test the use of the provisions by the rest of the Title II beneficiaries.

Certain portions of the bill have SSI implications and fall within this Subcommittee's jurisdiction. Other portions of the bill have Medicare and Title II implications and fall within the jurisdiction of the Subcommittee on Health and the Subcommittee on Social Security. We urge this Subcommittee to work closely with the Members of the other two Subcommittees to coordinate consideration of the various sections of the bill and to coordinate its passage by the full Ways and Means Committee for inclusion in the Committee's Fiscal Year 1990 budget reconciliation package. Passage of these bills would be a critical component in the effort to help many persons with disabilities become more independent.

"SSI Benefit Improvement Amendments of 1989", H.R. 866

1. Increase in the SSI benefit level (H.R. 361 and Section 101, H.R. 866)

An increase in the federal SSI benefit standard is desperately needed. Poor individuals and families who are solely dependent on SSI are living far below the poverty line. Steps should be taken immediately to increase the benefit level gradually over time to bring the amount up to the poverty line. The SSI program goal of guaranteeing a minimum level of cash to persons who are elderly or disabled has not yet reached the point of assuring that those persons can live even at poverty standards. It should be remembered that the poverty level only measures the cost of a low cost nutritional diet plus two times that amount for coverage of other basic necessities.

2. Increase in SSI resource limits (H.R. 360 and Section 201, H.R. 866)

The SSI resource limits are also drastically low ($2,000 for an individual and $3,000 for a couple). The resource limits do not enable SSI recipients, particularly those who work using the Section 1619 work incentive provisions, to save money to reasonably meet unexpected expenses or emergencies. A more realistic level should be set for the resource limits. H.R. 360 and H.R. 866 propose an increase to $4,200 for an individual and $6,300 for a couple which will restore the resource level to the approximate value of the resource limits in 1974, when the limits were first established.

3. Change in the treatment of in-kind income for persons living in the household of another (Section 102, H.R. 866)

Changes are needed regarding the calculation of the reduction of the federal SSI benefit level to account for in-kind support received by a beneficiary while living in the household of another. The calculation should be changed to call for a reduction equal to the lesser of the value of the current one-third reduction or the actual value of the assistance received. This provision would primarily benefit very low income persons where the value of the in-kind

assistance received is less than one-third of the federal benefit standard. This would affect persons in homes where household expenses are lowest and would remove a sort of Catch-22 which now hurts the very poorest of SSI beneficiaries.

4. SSI status to be deemed for certain persons with in-kind income (Section 103, H.R. 866)

Currently, there are many persons who have some non-SSI income (which may be income from Social Security Disability Insurance (SSDI)) and who also receive in-kind assistance. Many are not SSI eligible because, due to their receipt of in-kind income, in determining SSI eligibility, their other income is applied to the reduced SSI federal benefit level (two-thirds of full benefit level). This typically may happen to an adult disabled during childhood (DAC) who receives a relatively modest dependent's or survivor's benefit as a result of an insured parent's disability, retirement, or death. If the person lives at home with a parent or relative, application of the Social Security and other income against two-thirds of the federal SSI benefit standard may leave the individual ineligible for SSI, and therefore Medicaid, even though his cash income is less than the SSI standard. Section 103 of H.R. 866 would deem that person to be SSI eligible for purposes of Medicaid. For many persons with developmental disabilities, Medicaid eligibility is necessary in order to have certain non-institutional long term care needs met through Medicaid reimburseable programs.

5. Establishment of a permanent SSI outreach program (Section 301, H.R. 866)

To ensure that the maximum number of eligible persons are aware of and apply for their benefits under the SSI program, the Social Security Administration (SSA) should be required to engage in an ongoing outreach program. SSA is in a unique position to do two things:

1) identify those persons who apply for Title II retirement and disability benefits and their dependents who are likely to be eligible also for SSI; and

2) provide general and technical assistance to those federal, state, and private agencies and non-profit organizations who come in contact with other persons who are also likely to be eligible for SSI.

Special outreach efforts should be required to children who are disabled or blind since the avenues for identifying them will be different than those for adults. In addition, the Secretary of Health and Human Services should be required to evaluate the effectiveness of the outreach programs and to make an annual report to Congress. It should be made clear that SSA may fulfill some of its obligations under this section through contracting with qualified parties.

"SSI Technical Amendments of 1989", H.R. 867

1. Treatment of workers' compensation and unemployment compensation as earned income for SSI purposes (Section 101, H.R. 867)

Workers' compensation and unemployment compensation benefits should be treated as earned income for purposes of SSI. This proposed change could make a substantial difference to families struggling to meet expenses since earned income is treated more favorably than unearned income for purposes of SSI. Since workers' compensation and

unemployment compensation are paid to a worker as temporary compensation for or replacement of lost earnings, treating these payments as earned income would more realistically carry out the SSI purpose of supplementing an individual or family's earned income. Time and other constraints now placed on these awards should suffice to offset any deterrent to reentry to the workforce.

2. "Changes in eligibility determinations for weekly or biweekly income in certain months (Section 102, H.R. 867)

Changes are needed to resolve problems which beneficiaries encounter when they receive three biweekly or five weekly checks in a given month because of the way in which the weeks fall on the calendar. Curently, a person's SSI benefit is reduced or terminated when he/she or certain other family members receive an extra payment for the month. Section 102 would require the Secretary to consider the person's annual income and use an average monthly amount in calculating the SSI benefit.

3. Disregard of certain interest and dividend income (Section 105, H.R. 867)

This section would require the Secretary to disregard certain interest or dividend income equivalent to what the recipient might be expected to receive if he/she placed his/her disregarded assets in a savings account. This should encourage thrift at a time when capital formation is a desired fiscal policy objective.

4. Retention of Medicaid for additional adults disabled during childhood (Section 302, H.R. 867)

Currently, people who first become entitled to Title II disability benefits as adults disabled during childhood (entitled to benefits upon their parent's disability, retirement, or death) after July 1, 1987 are deemed to be SSI eligible for purposes of Medicaid eligibility. Section 103 would extend the date back to January 1, 1981 to cover more such persons who have lost eligibility to Medicaid due to Title II benefits. For these individuals, entitlement to Medicaid may be critical in paying for Medicaid-funded long term care services targeted specifically to persons with developmental disabilities.

5. Amendments to ensure appropriate transition to Medicaid for those deemed eligible (Section 303, H.R. 867)

Amendments are needed to address the problems encountered by people who lose eligibility for SSI cash benefits but who are deemed to be eligible for Medicaid benefits (such as certain adults disabled during childhood, who receive Title II benefits as described in Section 302). A smooth transition into continued Medicaid eligibility is a goal that has not yet been achieved. Currently, there may be a gap in coverage until they go to the state Medicaid office to apply for benefits or if they fail to apply. Section 303 would provide that such individuals would be presumed to have filed for Medicaid and that their benefits would continue unless they are determined to be ineligible. Section 303 would also establish timelines within which certain determinations must be made in order to be effective retroactively.

Section 303 also provides that these changes in Medicaid eligibility determinations are to apply in "Section 209(b)" states.

"SSI Disabled Children Act of 1989", H.R. 868

1. Changes to the definition of disability for children (Section 2, H.R. 868)

Comprehensive changes are needed in the statutory definition of disability for children in order to ensure that children with severe disabilities, who should be eligible for SSI, are properly identified and given benefits as early as possible. Congress is well aware of the benefits of providing needed services to children as early as possible to prevent the cummulative and costly effects of delay in providing those services. Section 2 would do several important things:

1) It would ensure that the Secretary will consider a child's functional limitations in determining whether a child meets the disability listings. This is not happening under current law and many children who are severely disabled are denied benefits because they do not meet the exact specifications of the impairment listings, regardless of their functional limitations.

2) It would create a presumptive eligibility for children who have congenital or genetic impairments if it is probable that, when more accurate testing is available, the child will be considered to be disabled.

3) It would require the immediate publication of proposed rulemaking for revision of the childhood mental disability listings. A draft listing prepared by the SSA Mental Impairments Listing Workgroup has gone unpublished for over three years. The changes are long overdue.

4) It would require the Secretary to consult experts in childhood disability to consider changes which should be made to the full listing of childhood impairments and to publish proposed revisions to the listings.

2. Amendments related to resources (Section 3, H.R. 868)

Two amendments are needed relating to counting of resources for SSI eligibility. Included in Section 3, the two amendments would significantly affect children with disabilities in poor families who are now found ineligible for SSI benefits because of the current very restrictive rules. The first would ensure that resource exclusions are counted for each family member, particularly siblings of the child who is disabled, whose needs must also be met. The second would eliminate the current rule that may require the family to liquidate resources essential to its self-support in order to obtain Medicaid for the child. It tends to have especially harsh effects on poorer farm families with a child who is disabled. The amendment would require that the value of income-producing property would not be counted as a resource; rather the income produced by the property would be considered as income in determining whether a child is eligible for SSI.

Section 4 is necessary to ensure that SSI eligible children are considered Medicaid eligible in all states. It will help to make eligibility for vital services a bit more uniform for children across the country.

The ARC wholeheartedly supports the bills discussed above and urges the Committee on Ways and Means to act expeditiously to pass them. We also urge the Committee to act expeditiously to make a statutory change in the substantial gainful activity (SGA) level to increase it to reflect the average wage growth since 1980 and to index it for inflation. Such a change would bring the level to about $520 per month in 1989.

Again, I thank the Committee Chairman and Members for your attention to these very important issues. We look forward to working with you further to ensure passage during this Congress.

Mr. ANDREWS. Mr. Gashel.

STATEMENT OF JAMES GASHEL, DIRECTOR OF GOVERNMENTAL AFFAIRS, NATIONAL FEDERATION OF THE BLIND

Mr. GASHEL. Thank you.

I am representing the National Federation of the Blind. The five areas I will highlight briefly touch upon the special concerns of the blind population and a distinctive category of the SSI program.

First is the income limits.

SSI's income limits were originally established in 1972, as you know, and they have not been revised since.

The original law guaranteed the recipient a basic income disregard of $85.

The unearned income disregard was supposed to be $20 but is now $6.90 in the current value.

The earned income disregard was set at $65 in 1972 and is now worth $22.42. Combined, these disregards are worth $29.42.

Congress should restore and maintain the value of the basic disregards in the program.

The restored value of the unearned income disregard should be set at $60 in January 1990 and at the same time the basic earned income disregard should be $190, which would fully restore its value.

Each of these amounts then should be adjusted by appropriate inflation percentage for each year beginning after 1990.

The income disregards are supposed to give SSI recipients the assurance of a minimum standard of living beyond the level of their SSI payments.

For a single individual living alone, for example, the program originally promised $140 a month in the standard payment amount plus $85 of exempt outside income for a total of $225 of spendable income to the SSI recipient.

In the interim 15 years of the operation of the program, it has not worked out that way.

The value of the basic standard of living should now be $650, but the recipient is only getting $453, which is about $200 less for the recipient who has any outside income.

The second area, and following a similar philosophy, deals with the resource limits which are now losing their value day-by-day and year-by-year.

The modest increases which Congress granted in recent years now pegging the resource limits at $2,000 for an individual and $3,000 for couples, still mean that you have to be the poorest of the poor to qualify.

The current value of the 1972 resources for individuals should be $4,335 and the value for couples should be $6,500.

We recommend that Congress establish those amounts and the resources limits should also be increased and indexed year by year to keep pace with inflation.

Moving to the third area, which is approval and use of plans for self-support under the SSI program, these should be improved.

A plan to achieve self-support is a mechanism in the SSI program in sections 1612 and 1613 of the act which give recipients the

chance to use income that they receive and resources that they may accumulate to help achieve financial independence. Having an approved plan to achieve self-support means that recipients will not have to sacrifice the needed income from SSI when they acquire certain funds or receive income to pursue vocational objectives.

The self-support plan is an under-used provision of the law.

Outreach should be required in the manner that I have specified in the written statement, Mr. Chairman, and also expedited approval of plans for self-support should be required by law, as I have suggested.

An unapproved plan for self-support during a period of specific training activities is worse than useless.

It is a promise of the law that has been denied administratively.

What we are suggesting is a 30-day approval opportunity for the Social Security Administration after which it should be presumed that the plan is approved and benefits should be adjusted accordingly until the plan is finally acted upon by the Social Security Administration.

Also, all SSI claims personnel need to identify potential candidates for developing plans for self-support and should assist recipients in developing these plans.

SSA's posture toward the use of plans for self-support should become proactive rather than reactive.

Four, the next area deals with targeted outreach to the blind.

Blind people are by far the smallest categorical group of the SSI population comprising about 2 percent of SSI recipients.

There are also some rules that are very specialized that apply uniquely to the blind and have been designed for this category.

For these reasons, obtaining uniformly accurate information in the application of the law to blind persons has been a recurrent problem.

Targeted outreach activities should be defined to give specific relevant information about SSI to blind people in an understandable and readable fashion.

Higher payment amounts do exist in some States for blind people. In the program as a whole, income may be disregarded when it is used to meet the ordinary and reasonable work expenses of a blind person, but if these features are overlooked because blindness is overlooked, the provisions will not be applied.

Outreach is in order.

Five, and finally and we think very importantly, we applaud the efforts of Mr. Ford on this subcommittee to bring about better rehabilitation options for blind people under his bill, H.R. 855.

This bill would give SSA the authority to contract with private and public agencies that provide employment and training services to blind people and to give blind recipients the opportunity to design their own programs and specify the service-providing agencies approved by SSA to provide those programs.

Under current law, SSI recipients must receive rehabilitation services from only the State vocational rehabilitation agency in their State.

There is only one per State, so the selection is down to one; there is no choice.

This restriction denies recipients the freedom of choice bill.

State restrictions for using funds for financing training in other States would be eliminated.

Most importantly, the adult blind recipients who would benefit from Mr. Ford's bill would be treated as responsible thinking adults who are capable of planning and carrying out their own futures.

Rehabilitation programs work best when the recipient has been personally invested in the outcome.

This is more likely to be the case if the recipient, not the State, chooses the program to be pursued.

Therefore, we support and we hope this subcommittee will include in an SSI improvements bill the provisions described.

With that, I will cease and thank you on behalf of the National Federation of the Blind.

Acting Chairman DOWNEY. Thank you.

[The statement of James Gashel follows:]

BEFORE THE SUBCOMMITTEE ON HUMAN RESOURCES

COMMITTEE ON WAYS AND MEANS

UNITED STATES HOUSE OF REPRESENTATIVES

WASHINGTON, D.C.

STATEMENT OF THE

NATIONAL FEDERATION OF THE BLIND

JAMES GASHEL

DIRECTOR OF GOVERNMENTAL AFFAIRS

MAY 30, 1989

Mr. Chairman, I am James Gashel. I am Director of Governmental Affairs for the National Federation of the Blind (NFB). My address is 1800 Johnson Street, Baltimore, Maryland 21230. Thank you for offering me this opportunity to present the views of the National Federation of the Blind in response to the Human Resources Subcommittee's interest in reviewing proposals to improve the Supplemental Security Income (SSI) program for the aged, blind, and disabled.

There are over fifty thousand blind people who are members of the National Federation of the Blind. We have a local chapter of the Federation in almost every sizable population area in this country and a state affiliate in all states and the District of Columbia. In short, Mr. Chairman, the National Federation of the Blind is organized and active in all parts of the United States.

By virtue of its size and scope the National Federation of the Blind represents and speaks for the blind as a collective body. We speak for older blind persons and younger blind persons as well. The positions we express in hearings such as these are the result of the democratic process of debate and decision making. The supreme authority of the Federation is its National Convention, which occurs annually. During the convention we openly debate (and approve or disapprove) a number of policy resolutions. In this manner the Federation is truly the blind speaking for themselves. It is not simply an organization speaking for the blind. All of our elected officers and the vast majority of our members are blind. For these reasons the Federation is widely known as the voice of the nation's blind.

We welcome the opportunity, Mr. Chairman, to explain how in our view the SSI program can be improved. The population of blind SSI recipients is by far the smallest of the three eligible categories, representing fewer than 85,000 individuals. Approximately 2 percent of the SSI population is blind. At the same time there are several unique features of the law which require the Social Security Administration to treat the blind distinctly from other beneficiaries. This information is offered by way of background and gives rise to our recommendations for specific outreach activities. Other concerns we have relate to updating provisions of the SSI law that have not been changed since the program began in 1974.

(1) Exempt Income Increase: Section 1612(b) of the Social Security Act should be amended to restore the value of exempt income which Congress established in the original SSI law. The basic exempt amount of monthly unearned income is $20, after which SSI payments are cut dollar for dollar. The basic monthly earned income exclusion is $65 plus up to $20 of unearned income, for a total of $85. Half of a recipient's earnings above the basic exclusion amount applicable are also exempt. All of these values are unchanged from the original SSI law.

These exempt amounts were included in the SSI law as stated in 1972 dollars. But the dollar of 1972 is worth 34.5 cents as of April, 1989. Today's recipient needs $2.89 to purchase the same product that could have been bought for $1.00 in 1972. The values of the income exclusions for SSI recipients have thus been eroded. This erosion, month-by-month, year-by-year, actually reduces the total amount of money available to SSI recipients. The recipients who have a source of small income other than SSI are actually denied the full value of the annual cost of living adjustment that the law requires for SSI payment amounts. Even though the cash benefits are increased automatically because of inflation, the exempt amounts are not. The incentive for recipients to work and receive income outside of SSI is also diminished as the value of the exemptions grows smaller. Rather than permitting this, Congress should be trying to increase the work incentives.

It is time for Congress to end this particular inequity in the SSI program. The principle of exempt income was an important cornerstone of the law, although the $20 and $65 basic exclusions were never regarded as particularly generous. Certainly these amounts were not excessive even in their original values. The law should now be amended to restore the original exemptions. Beyond that, the exemptions should be indexed to inflation to protect their value against future erosion. Specifically, the amount of monthly unearned income allowed should be increased to $60, effective January 1, 1990. Similarly, the amount of monthly earned income allowed should be increased to $190. The maximum income exemption would thus become $250 as compared to $85 presently. I should emphasize that in January, 1990, these will be the approximate values of the original 1972 exemptions. This is no more than the law promised.

(2) Resources Increase: Section 1613(a) of the Social Security Act should be amended to restore the original value of resources allowed for SSI recipients. The resource limits were originally $1,500 for individuals and $2,250 for couples. These amounts have now been increased in stages to $2,000 for individuals and $3,000 for couples. There are no scheduled increases under current law.

Full restoration of the 1972 resource limits would now allow individuals to retain $4,335 and couples to have approximately $6,500. The failure by Congress to make adjustments in the resource limits (at least enough to keep pace with inflation) means that the SSI program serves an increasingly poor population of aged, blind, and disabled persons. The recipients who now qualify are beyond a doubt the poorest of the poor in these categories. We propose increasing and indexing the SSI resource limits to their comparable 1972 values. This would not mean a change in program philosophy or target population. It would not mean that the SSI program would begin to serve the well-to-do. It would mean that the individuals and couples who do qualify could have greater assurance of meeting emergency needs (health or otherwise) that arise from time to time. It would also mean that these recipients could begin to save a little in order to improve their condition. Most importantly, it would mean an opportunity for these individuals and couples to live with greater dignity and independence.

(3) Improvements in the Use and Approval of Plans to Achieve Self-Support: Sections 1612(b) and 1613(a) of the Social Security Act should be amended to improve the application of provisions for exempting income and resources under approved plans to achieve self-support. The current sections generally authorize such plans which may be established under regulations of the Secretary. The regulations allow for a blind or disabled recipient to establish a plan to achieve self-support for an initial period of 18 months, with extensions that may be authorized for up to 48 months. Generally, any income or resources of a recipient that are necessary to complete the self-support plan, as approved by the Social Security Administration, may be disregarded in determining eligibility or the amount of

the payment due a recipient who has an approved plan.

Outreach by the Social Security Administration to inform blind people of the potential uses of plans to achieve self-support is almost totally nonexistent. Several years ago the National Federation of the Blind called attention to this problem and even offered to prepare a draft publication aimed at the SSI blind population. SSA officials were receptive, but time and resources have not permitted us to write, publish, and distribute a special guide on using SSI's provisions for the self-support plan. We recognize a responsibility (and certainly a desire) to inform those we can reach. The Federation is regarded by the blind as a knowledgeable source of accurate information on SSI issues. However, the responsibility to perform an SSI outreach function is not solely (or even principally) ours.

All SSA personnel who assist in filing, revising, or reviewing claims should be alert to inform applicants or recipients of the possible advantages in having an approved plan to achieve self-support. Under present conditions it is our experience that the applicants or recipients must have independent knowledge of the self-support plan option, and they must take the initiative to request the interviewer's assistance. Even then the results in having the law applied without confusion or difficulty are mixed at best. Specific outreach activities should be directed in the law. These activities should include alerting recipients of the potential uses of the self-support plan and individualized assistance in developing an approvable plan. Special forms for this purpose should be readily obtainable at all Social Security offices.

Expedited approval of self-support plans is also essential and should be required by law. The very nature of a plan for self-support is that activities, such as training programs, must be undertaken during a certain period of time. Notice several months in advance is not always possible. If timely approval is not given, the opportunity might be lost or significantly delayed. In more than one instance in my experience SSA's approval time for the plan to achieve self-support has exceeded the length of an entire academic year and extended into another. When this occurs the disruption in a recipient's plans and progress is discouraging to say the least. If the training opportunity is postponed, it is a costly delay to the taxpayers. If the opportunity is pursued without SSI support until the approval of the plan is given, a substantial back payment may be due. In either case, the goal of the law, to promote self-support is not being fulfilled. To resolve this difficulty a statutory 30-day deadline for approving self-support plans should be imposed on SSA, after which an assumption of approval should be made and benefits adjusted accordingly.

(4) Outreach on Special Eligibility Rules for the Blind: Congress should direct the Social Security Administration to undertake specific outreach activities aimed at eligible (or potentially eligible) persons who are blind. Communicating and applying accurate knowledge about the SSI program for blind persons has been a recurrent problem since 1974. SSA is certainly capable of making outreach efforts as demonstrated by its promotion of the new section 1619 program. However, these more recent activities have tended to overshadow the very specialized provisions that must be applied by law to blind SSI applicants or recipients.

Erroneous determinations that a blind person is not "disabled" (and therefore ineligible to receive SSI payments) occur more frequently than you can imagine. The law, of course, requires that the person be "blind," whether or not disabled. In fact, a determination of disability is not relevant in blindness cases because blindness is statutorily defined. Outreach activities should emphasize that blindness is a defined category in SSI. A person is blind by definition if the visual acuity and/or field of vision meets the restrictions listed in section 1614(a)(2) of the Social Security Act. It is not necessary for

the same person also to be disabled. Disability and blindness under SSI are separate categories.

If a person is found to be blind, whether or not disabled, several other provisions of the law are supposed to take effect. In a few states, a higher rate of state supplementation is paid to the blind as a categorical group. In the program as a whole, working blind persons may have excluded from their income the actual amount of "ordinary and reasonable work expenses." In the case of persons who are disabled but not blind, the law provides for deducting the cost of impairment-related work expenses. There are important differences in these deductions, and they definitely affect SSI payment amounts. It is therefore important that SSA personnel, as well as blind applicants, have accurate and specific information.

The small size of the blind SSI population, as compared to seniors or the disabled means that SSA personnel have fewer opportunities to apply the relatively specialized SSI blindness provisions. This fact alone should justify some targeted outreach initiatives. In addition, all of SSA's public information pamphlets are written to reach a more general audience. Provisions that apply across the board, and especially to the two larger groups--the aged and the disabled, get the most attention. The fact that special rules exist (or may exist) for the blind is mentioned less prominently and in less detail. The availability of accurate information for the blind and its accurate application in blindness cases would both improve with a plan for ongoing outreach to the blind. Resources permitting, the National Federation of the Blind would certainly be happy to co-operate and increase our current work in this area.

(5) Use of Recipient-Selected Referral Sources for Rehabilitation: Section 1615 of the Social Security Act should be amended to permit blind recipients to obtain vocational rehabilitation services from public or private agencies selected by them. The current law limits recipients to the use of state vocational rehabilitation agencies having approved state plans under title I of the Rehabilitation Act of 1973, as amended. There is one (and only one) such agency to serve the blind in each state.

Congressman Harold Ford, a distinguished member of this subcommittee, has introduced H.R. 855 to accomplish the purpose we endorse. His bill would give blind recipients the opportunity to select, design, and pursue rehabilitation programs that are individually developed by and for them. The agency, institution, or individual from which rehabilitation services are obtained would also be chosen by the blind individual. Service plans and arrangements would be subject to approval by the Social Security Administration. Private agencies that provide services to the blind under this bill would do so under contract with SSA. Advance funding to pay the costs of obtaining services from such agencies should be available.

The program Mr. Ford has proposed would be a natural adjunct to the existing exclusive use of state vocational rehabilitation agencies. It would leave the existing state programs intact with all of their present financial support now provided under the Rehabilitation Act. The difference for the recipient would be greater selection of relevant services. The recipient would not be limited to services available through assistance by a single agency in each state. State boundaries (and limits on out-of-state expenditures) would not prevent finding the best program for each individual. Under H.R. 855, a source of funding (not tied to any particular state or to any agency) would be available for any blind recipient who wanted to exercise a free choice.

To the extent that this program would stimulate competition among agencies to make their philosophies and programs attractive to potential blind participants, funding of rehabilitation services as described in H.R. 855 would create a healthy, new environment full of new opportunities and promise for the future.

In addition, funds paid to enable blind recipients better to achieve their training and employment goals will reduce demands for continuing cash outlays of SSI funds. This is a cost-effective approach that Congress should now enact.

Mr. Chairman, thank you for this opportunity to advise the subcommittee on several matters that we feel need urgent attention in the SSI program. In general this is a good program, but improvements can and should be made. This is certainly true with reference to the income and resource limits that are gradually but steadily being eroded. Also, the time has finally come to improve the application of the plan for self-support provisions in the program and to give blind persons improved opportunities for rehabilitation. Mr. Chairman, on behalf of the National Federation of the Blind, I thank you for your attention to these proposals. With your continued assistance and that of this subcommittee the SSI program will become an improved source of security and self-help for blind individuals and couples who need it.

Acting Chairman DOWNEY. Mrs. Hickey.

STATEMEMT OF SYDNEY T. HICKEY, DIRECTOR OF GOVERNMENT RELATIONS, NATIONAL MILITARY FAMILY ASSOCIATION

Mrs. HICKEY. The National Military Association appreciates this opportunity to express its views on H.R. 874 introduced by Congressman Slattery.

Sergeant Major McKinney had to leave. I will ask that my statement be made part of the record.

Acting Chairman DOWNEY. All the statements will be made a part of the record.

Mrs. HICKEY. In my travels through Germany last week, I spoke with Army families who have handicapped children and who received SSI while stationed in the United States. I also talked with Red Cross and Army Community Service volunteers who tried to assist these families and with exceptional family member program managers and social workers who deal with these families on a daily basis.

I must report the level of frustration and, yes, even anger, is high. Neither the professionals who treat these families, the volunteers who attempt to get community resources for them, nor the families themselves can understand why SSI benefits are cut off simply because they are overseas on orders of their own government.

Four-year-old Aaron and his 9-year-old sister are in Stuttgart, Germany, where their Army father is stationed. Aaron was accepted into the SSI program in the States because he has Down's syndrome complicated by severe respiratory problems. In September 1987, his father was transferred to Germany, and Aaron's payments stopped. His mother has tried to find work to cover the cost of baby food, adult diapers and special clothes. In order to have one play suit for Aaron, she must buy two, as upper body and lower body are not the same size. She has gone through 35 baby-sitters and is unable to find a job with wages that exceed the cost of child care for Aaron.

Sergeant and Mrs. Cameron Cloud are stationed at Friedberg and have two children, Rebecca, age 12, and Lucas, age 4. Lucas has cerebral palsy. Both of Lucas' hips had to be broken and metal plates inserted in order to reposition his legs so he would be able to walk. Because Mrs. Cloud cannot handle Lucas in his body cast, Sergeant Cloud is presently on leave. Mrs. Cloud has taken a temporary job to attempt to save money for Lucas' needs, including special shoes when he gets out of his cast. Twelve-year old Rebecca is her only source of affordable care. Lucas lost his benefits when he accompanied his father to Germany in the summer of 1986.

Sgt. William Long and his wife, Shirlena, have a 17-year-old son named Stacy. Stacy has been severely retarded since he had spinal meningitis at 9 months of age. Stacy has three brothers and one sister and has been in the program since 1975. He does not walk or talk and cannot perform any function for himself. Stacy must be fed his baby food, have his adult diapers changed and be carried from room to room. His shoes must be ordered from the States, and he needs special clothing.

In July 1987, Sergeant Long was ordered to Lanstuhl, Germany, and Stacy's SSI payments stopped. The only way Sergeant and Mrs. Long can go out for a walk in the evening is to leave his 14-year-old sister, Tara, in charge of Stacy. They cannot afford the $10 an hour adult baby-sitter's charge to care for their son.

Mr. Chairman, sitting at this witness table with me are not only the families I have mentioned or the couple of hundred handicapped children H.R. 874 would benefit, but over 1,000 military family members with whom I spoke in Germany. I can't begin to describe the joy that they expressed when told a soldier's one letter to a single Congressman resulted in this hearing today. Certainly the intent of the original supplemental security income legislation could not have been to exclude military families merely because they are stationed overseas, and NMFA, along with the Non-Commissioned Officers Association and eight other national and international military organizations strongly support H.R. 874 to correct this inequity.

However, perhaps of almost equal importance is the message that passage of this legislation will send to military families worldwide. The message that the problems of even a small number of them are not insignificant to you. That indeed you do care about them as people and not just as numbers.

Thank you.

Acting Chairman DOWNEY. Thank you.

[The statement of Sydney T. Hickey follows:]

STATEMENT OF SYDNEY T. HICKEY, NATIONAL MILITARY FAMILY ASSOCIATION, INC.

The National Military Family Association (NMFA) is a volunteer organization composed of members from the seven uniformed services, active duty, retired and reserve, and their family members and survivors. NMFA is the only national organization whose sole focus is the military family and whose goal is to influence the development and implementation of policies which will improve the lives of those family members. NMFA appreciates this opportunity to express its views.

NMFA supports H.R 874, a Bill to amend title XVI of the Social Security Act to provide that a blind or disabled child otherwise qualified may be eligible for Social Security Income (SSI) benefits even though not a resident of the United States, if such child is accompanying a parent who is a member of the Armed Forces serving a tour of duty overseas.

Under current law, children eligible for SSI payments lose these payments when they accompany their military parent overseas. A child is eligible for SSI when he or she is severely disabled or impaired. Eligibility for SSI is also contingent upon the income of the family. The child of a military family eligible for SSI in the United States should not have federal social security funds withheld when the military parent is ordered overseas.

An E-3 military member with a family receives $1,368 a month in pay and allowances. The SSI payment to a disabled child of an E-3 is approximately $245.34. The loss of that payment is equal to 18% of the total family income.

The loss of SSI payments impacts severely on the well being of the disabled child. These payments help offset the extra costs involved in allowing the child to maintain a minimum standard of living. The child's needs remain the same whether the family is stationed in the United States or overseas. In fact, necessary services such as respite care, goods, clothing and nutritional needs may be more expensive overseas because of the fluctuation of the dollar.

Withdrawal of SSI payments will result in dramatic reduction of resources for eligible children of military members stationed overseas. Since the military member serving overseas loses earned income credit, the additional loss of SSI payments will cause further economic hardships. The combined monthly loss of earned income credit and SSI payment is $310.34 for the E-3 family. Because of financial constraints, parents will likely have to forego necessary goods and services for the disabled child and go deep into debt for years to come.

NMFA, together with the Non-Commissioned Officers Association (NCOA), urges this subcommittee to support H.R.874. The following associations also support this measure: the National Association for Uniformed Services (NAUS), The Retired Officers Association (TROA), The Retired Enlisted Association (TREA), the Marine Corps League, the U.S. Coast Guard Chief Petty Officers Association, the Fleet Reserve Association (FRA), the Naval Enlisted Reserve Association (NERA), and the Air Force Sergeants Association.

H.R.874 is a bill that will significantly affect the lives of an estimated 200 disabled children who need your help.

Acting Chairman DOWNEY. Ms. Disher.

STATEMENT OF CHRISTY DISHER, PRESIDENT, NATIONAL MENTAL HEALTH CONSUMERS ASSOCIATION, REPRESENTING THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

Ms. DISHER. Thank you for this invitation to testify.

My name is Christy Disher, and I am testifying on behalf of the National Alliance for the Mentally ill. NAMI is a national network of 60,000 families whose lives have been directly affected by a mental illness. My husband and I have recovered to a large extent from mental illness and for the past 6 years we have worked as advocates on behalf of persons with a mental illness.

I am currently the president of the National Mental Health Consumers Association. The NMHCA is a national advocacy organization with a membership of over 5,000 persons who are currently and former mental patients. Five-hundred organizations are members of the National Mental Health Consumers Organization. Most of these organizations are self-help programs run by mental health consumers themselves, and my husband, Brian, and I created such a self-help program 6 years ago in Rockville, Md., in Montgomery County, called On Our Own of Montgomery County, and we do mutual support, socialization, and we also advocate for ourselves, like I am trying to do today.

And this reflects an exciting development in the mental health field as patients, mental patients, are becoming empowered through their involvement in self-help programs, such as our own and the National Mental Health Consumers Organization, and we are having an impact on the mental health system itself.

I have submitted written testimony, and I am readily available to answer questions regarding a very serious problem that I and many persons I advocate for have encountered while trying to recover from mental illness. That is the Social Security Administration and SSI. I recognize that your committee and others in Congress have made substantial efforts to write laws designed to make the system more accessible and fair for us. However, there remains significant problems in the way the SSI program is administered.

I have six points to make, and I will try to make them briefly. They are covered in more detail in my written testimony, which NAMI helped me to write. You have heard testimony from panelists before me discussing various legislation which is pending before your subcommittee. NAMI supports the passage of all legislation which improves upon current SSI laws and the manner in which the program is administered, and we especially are supportive of H.R. 866 and 868.

I would like to devote the rest of my testimony to several general issues which particularly concern people with mental illness and their families. To improve access and outreach, Social Security personnel should spend some of their time with the seriously mentally ill persons where they work and where they spend their day. Social Security is like an inpenetrable fortress. A simple thing like making a name change took someone I knew several years in writing and on the telephone and still to this day Social Security has the name wrong. Social Security representatives should come to

family and consumer groups like our drop-in center for a meeting of the Alliance for the Mentally Ill to provide information about the Social Security Administration.

The recent SSI Improvements Act made some important changes in the laws designed to reduce work incentives. However, there still remains significant incentives particularly with regard to potential loss of Medicaid benefits. Unfortunately, few health insurance policies offer mental health benefits which are equivalent to those offered under Medicaid. The insurance industry still provides limited coverage for treatment of mental illness.

Mentally ill people have a hard time advocating for themselves. Therefore, persons with mental illness risk losing coverage for needed treatment when they return to the work force. So we don't want to go back to the work force, and we are terrified we will lose our benefits. We urge you to consider this in drafting future legislation.

We recommend that the SSA, the Social Security Administration, focus energy into encouraging State DDS's to better train disability customers, and we also recommend that the reconsideration level be eliminated in the appeal process. Because while this yearlong appeal process is going on, the person has no income. They just wait too long.

I am almost finished here. The last couple points have to do with the case-workers in the local offices. They are ill trained and totally insensitive to the needs of mentally ill people. The Social Security Administration's desire to automate everything really shows a lack of awareness about the needs of disabled persons. The use of automated systems should not be an excuse to have case-workers in the local offices. I recommend that as mental health consumers, we be involved along with the family members and mental health professionals in training these case-workers in the local Social Security office. We have a sensitivity to the illness and a certain expertise to impart to the caseworkers.

Finally, Mr. Chairman, I have one last thing to say, and that is that it is clear that the Social Security Administration is determined to do nothing to help prospective beneficiaries unless compelled to do so by law. This is why we are so appreciative of the efforts of your committee. Mentally ill persons have difficulty advocating for their needs, and we need your help.

Thank you.

[The statement of Christy Disher follows:]

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STATEMENT OF CHRISTY DISHER, REPRESENTING THE NATIONAL ALLIANCE FOR THE MENTALLY ILL (NAMI) BEFORE THE HOUSE COMMITTEE ON WAYS AND MEANS SUBCOMMITTEE ON PUBLIC ASSISTANCE AND UNEMPLOYMENT COMPENSATION, MAY 30, 1989:

Mr. Chairman, Distinguished Members of the Subcommittee:

My name is Christy Disher and I am testifying on behalf of the National Alliance for the Mentally Ill, (NAMI), a National network of 60,000 families whose lives have been directly affected by a mental illness. In addition to my membership in NAMI, I am the President of the National Mental Health Consumers Association, a national advocacy organization with a membership of over 5,000 persons who are current and former patients and consumers of mental health services. Finally, along with my husband Brian, we created and operate a drop-in center in Rockville, Md. called "On Our Own", where persons with mental illness can go for peer support, socialization, and opportunities to be involved in advocacy efforts. This reflects an exciting development in the mental health field, as patients are becoming empowered through their involvement in self-help programs such as this one and consequently are having an impact on the mental health system itself.

As a former patient, I have had direct experience with SSI and with the Social Security Administration. I currently work with and advocate for many persons who are SSI recipients or who are seeking to obtain these benefits. I recognize that your committee and others in Congress have made substantial efforts to write laws designed to make the system more accessible and fairer to those who are beneficiaries or potential beneficiaries. However, there remain, in my opinion, numerous and significant problems in the way that the SSI program is administered which ultimately hurt many whom the program is designed to help.

A discussion of these problems should begin with the difficulties which SSI applicants, beneficiaries, and disability advocates have in obtaining accurate information from the SSA. As you know, the process of applying for benefits is a complex one. There are medical, economic, and social factors which are considered in the process of making determinations of eligibility for SSI. The burden of proof currently falls squarely on the applicant to produce comprehensive information to enable the SSA to make fair SSI eligibility determinations. Because of this, many applicants are compelled to seek assistance from advocates in pursuing these benefits. Sadly, many persons with mental illnesses do not have access to such advocates. This is particularly true for those most in need of SSI benefits, persons with serious mental illness and persons who are mentally ill and homeless.

In our view, the Social Security Administration has made little progress in addressing these access problems. There are numerous steps which the agency could take in reaching out to those who are most in need of these benefits. Yet the current trend appears to reflect a move away from improving access. Let me give you a few examples.

The caseworkers in the local Social Security field offices often seem ill-trained to effectively communicate with persons who are severely disabled. This is particularly true for persons with serious mental illness. These caseworkers are overburdened with cases and therefore seek to move applicants in and out as quickly as possible. They often ask questions in quick, impersonal manners and become impatient if the applicant is not able to comprehend and answer as quickly as they would like. This cannot be attributed to isolated instances which involve examiners with poor

interpersonal skills. This rather reflects the lack of emphasis which the agency puts on training its caseworkers to effectively assist applicants. The fair and kind treatment of applicants, many of whom have dealt with extreme trauma and stigma in their personal lives, is simply not a priority of the current administration of the SSA.

This is further illustrated by the current "romance" which the SSA has with automating the application process. The Agency has come out and stated that its sophisticated plans to develop a nation-wide telecommunications system will result in less need for caseworkers at local levels. This is nothing short of absurd! This new system has already been implemented in certain areas and has reportedly resulted in further frustrations for applicants seeking to obtain accurate information in processing their claims. People attempting to reach caseworkers have encountered answering machines or worse, have been put on hold and finally informed that the person handling the particular matter will call them back. This wouldn't be so bad if the return calls were received in a timely fashion but they are often not received for several days or even weeks, and sometimes not at all. The Agency's insistence that automation can work reflects its complete lack of understanding about the need applicants have for face to face contact with persons who are understanding and willing to help them with their claims. Moreover, many persons with serious mental illness require patience and kindness. They do not do well in dealing with complex, impersonal, automated systems.

We therefore recommend that all caseworkers receive comprehensive training in how to communicate with applicants with mental illness in an effective, empathic manner. This could include training conducted by mental health professionals, family members, and consumers designed to familiarize caseworkers with mental illness and the problems experienced by those with these illnesses. We further recommend more caseworkers be hired to speak directly to applicants and their advocates. The advent of improved technological procedures should not be viewed as justification for placing less emphasis on the need for caseworkers.

The criterion utilized in determining eligibility for SSI benefits on the basis of "mental impairments" was revised approximately four (4) years ago. The new emphasis was to be on evaluating the impact which a person's mental illness had on his/her ability to function socially and in job settings. We applauded the wisdom of these changes. Today, we question whether this new criterion is being uniformly applied to persons with mental illness who apply for these benefits. In our experience, the disability examiner responsible for determining eligibility may in some cases properly call upon a variety of sources of information about an applicant, e.g. family members, the applicant him/herself, the treating Psychiatrist, Social Workers, Vocational Rehabilitation Counselors, etc. In other instances, an examiner may restrict his/her analysis to information received from the primary source of medical treatment. Often, these are not the best sources of information about the impact an illness has on an applicant's daily life. The determination of eligibility for SSI should not rest upon varying degrees of proficiency and concern among those vested with responsibility for making such decisions. Although the standards for determining medical eligibility have been improved, these standards must be uniformly applied if they are to be effective.

The SSA has acknowledged the need to conduct "outreach" efforts to locate and receive applications from hard to reach potential beneficiaries. We have yet to see evidence that these outreach efforts are in fact being conducted. We urge the Administration to place renewed emphasis in this area.

There are numerous persons with severe mental illness who are unaware of the availability of SSI and related benefits or how to obtain them. Outreach should focus not only on informing service providers but also on informing persons with disabilities, their families, and their advocates. For example, outreach could be targeted at shelters for the homeless, and drop-in centers such as the one which we operate. SSA representatives could also attend and speak at meetings held by local Alliances for the Mentally Ill which exist throughout the country. An Alliance meeting would be an ideal forum for an SSA representative to speak and provide needed information to families and consumers. I know that this would be greatly appreciated by the recipients of the information and consequently would be favorable to the SSA from a public relations standpoint.

We are additionally concerned about the current process for appealing SSI decisions. An April, 1989 report released to the Subcommittee on Social Security, House Committee on Ways and Means, by the General Accounting Office revealed that over 60% of all initial disability decisions by Disability Determination Services (D.D.S.'s) get overturned at the hearing level by Administrative Law Judges (A.L.J.'s). We do not have statistics on this, but we suspect that the statistic is as high or even higher for decisions concerning mental impairments. It has been widely reported that the SSA has been exerting pressure on A.L.J.'s to make fewer allowances. If so, the Agency is once again pursuing a misguided and mean-spirited remedy. The A.L.J.'s base their decisions on comprehensive review of all of the evidence. When complete evidence has not been received, they ask questions designed to bring out needed information. In essence, they are doing what the Disability Examiners failed to do at the initial and reconsideration levels.

SSI is an entitlement and is generally the means of last resort for those who receive it. It is essential that the SSA take all steps to ensure that those deserving of SSI benefits receive them. Too often, it seems to us that the SSA views its primary purpose as saving federal monies by eliminating or keeping people from its roles. We recommend therefore that the SSA focus energy into encouraging state D.D.S.'s to better train Disability Examiners. This is the best way to eliminate the discrepancy between the wrong decisions made at the initial and reconsideration levels and the right decisions made at the hearings level. We further recommend that the reconsideration level be eliminated. Too often, the reconsideration process is merely a mirror image of the initial stage. The G.A.O. study referred to earlier revealed that only 14% of initial decisions are reversed at this secondary stage. It therefore seems that the primary purpose of this stage is to increase the time it takes for an application to move through the lengthy application and review process. For those who in fact are deserving of SSI benefits but have been turned down at the initial stage, this means that they often have to wait for more than a year from application to a final determination of eligibility by an A.L.J. During this period, this severely disabled applicant may be without any means of income whatsoever.

The recent SSI Improvements Act has made some important changes in the laws designed to reduce the disincentives which exist to return to or initially enter the workforce. However, there remain significant disincentives, particularly with regard to Medicaid benefits. Under current law, former SSI recipients can continue to receive Medicaid benefits on a limited basis (if his/her salary is too high to continue to receive SSI, but too low to pay for the equivalent of Medicaid benefits). There are several problems under this law specific to persons with mental illness. First, there are few health insurance policies which provide benefits for mental health treatment equivalent to those available under

Medicaid. The Insurance Industry continues to practice blatant discrimination by virtue of limited or even non-existent coverage for treatment of long-term mental illness. Second, insurance policies provided by employers generally do not provide coverage for "pre-existing" conditions, thereby excluding mental health coverage.

We realize, Mr. Chairman, that this is not exclusively the concern of your committee. However, this factor constitutes an important and legitimate disincentive for persons with mental illnesses to "take the plunge" into the workforce and we therefore urge you to take this into consideration in future legislative initiatives.

Finally, we wish to comment on several important pieces of legislation which are currently before your committee. The "SSI Benefit Improvement Amendments of 1989" (H.R. 866) is important for several reasons. First, it calls for the monthly SSI benefit level to be increased to the poverty line by 1992. SSI beneficiaries are currently faced with a "Catch 22" dilemma. On one hand, it is next to impossible to live on the amount which they currently receive every month. On the other, the rigid regulations which limit the assets which beneficiaries can have and retain their eligibility for SSI precludes them from taking steps to alleviate their exclusive financial dependence upon their SSI checks. We realize that there is a steep price tag attached to this portion of the bill, but we emphasize its importance and urge the committee to press forward in seeking its passage. To borrow a phrase used by many, the budget must not be balanced at the expense of those who are most needy.

The modification of the standards for reduction of "in-kind" income is significant as well, particularly the provision which would allow those deemed ineligible for SSI benefits because of "in-kind" income to nevertheless receive Medicaid. If passed, this provision will allow families to provide more assistance to members who are mentally ill without having to worry about loss of needed medical benefits.

Finally, the "SSI Disabled and Blind Children Act of 1989" (H.R.868) is extremely important and should be pressed forward as well. There is increasing evidence that many adults with mental illnesses first experience their symptoms during childhood and adolescence. Yet the children's listings of mental impairments is outdated and not clear in its application. We have heard that specific recommendations for revising these "listings" were submitted to the SSA by a specially designed taskforce in 1986. Yet the Agency has done nothing to adopt or revise these recommendations, despite repeated assurances that they were indeed studying the recommendations. Three years is long enough, Mr. Chairman. Once again, it is clear that the SSA, under its current leadership, is determined to do nothing to help prospective beneficiaries unless compelled to do so by law. This is why we are so appreciative of the efforts of your Committee in this regard.

In closing, we thank you for the opportunity to express our concerns and recommendations before this important Committee. There unfortunately remain many significant problems with the SSI laws, regulations, and the way in which the program is administered by the SSA. Many of the changes we have recommended do not require excessive additional federal expenditures. Rather, they require wholesale changes in the "mindset" which currently pervades the leadership of the SSA. We hope that your Committee will continue to work towards changes through revisionary legislation and the creation of forums in which advocacy groups can express their views and concerns. Ultimately, the well-being of our nation is tied into the fair and equitable administration of programs such as SSI.

Acting Chairman DOWNEY. On behalf of the other members of the subcommittee, I want to thank you for taking the time to come testify today. I think you are going to be pleased with some of the work of the subcommittee, and we will ask you as time goes on to lobby our colleagues in the Senate and to lobby other Members of the House of Representatives as well.

We are just one subcommittee. We comprise a small fraction of the Members of the House, and while we hear on a regular basis of the problems involving recipients, this is not something that is in the forefront of other Members of Congress who have other responsibilities. So we need your persuasive intervention on their behalf sometimes to get this enacted.

Ms. Hickey, you are right, one letter can do it all. Your letter went to Mr. Slattery, who is a champion of individuals who have problems, and he has been persistent in his lobbying of me to be sure it is part of this effort, so the letter went to the right Member of Congress.

Also, we appreciate, as we said before, all of the time and effort you have given to us today. Thank you very very much.

Mr. Andrews, any questions?

Mr. ANDREWS. No.

Acting Chairman DOWNEY. The subcommittee stands adjourned.

[Whereupon, at 4:05 p.m., the hearing was adjourned.]

[Submissions for the record follow:]

STATEMENT OF THE HONORABLE CHESTER G. ATKINS

TESTIMONY FOR H.R. 1525

Thank you Mr. Chairman and Members of the Committee for this opportunity to testify on behalf of H.R. 1525. My colleague Brian Donnelly and myself introduced this legislation to correct a serious and tragic inequity in the Supplemental Security Income deeming laws for families with severely disabled children. This inequity was brought to my attention by Mrs. Kathleen Mulligan, a courageous and dedicated parent who wants nothing more than to care for her three-year old severely disabled daughter at home.

Under current law, a family with a severely disabled child is eligible for SSI and Medicaid benefits only if the child is hospitalized or institutionalized. If a family wishes to care for their child at home, they will lose their SSI and Medicaid benefits even if home care is cheaper than hospital care. This is because under current deeming laws, the parent's income and assets are deemed to the child only when the child is cared for at home. For nearly all families above the poverty level, this means the loss of SSI and Medicaid benefits.

This policy is not only cost inefficient for the federal government, it is harmful and inhumane to families who wish only to stay together. Medical and psychological studies have shown that home care is much more beneficial for severely disabled children and their families. It is common sense that the love shared between child and parent cannot be replaced in a hospital or institutional setting. Yet we have a policy that rewards parents for sending their child to an institution and punishes parents for caring for them at home.

It is time to correct this serious inequity in the deeming laws. It is unconscionable that we have a policy that makes it financially better for parents to place their child in an institution. With the passage of this legislation, our social policy can be more humane for the entire family as well as cheaper for the federal government.

Under H.R. 1525, the income deeming laws would be changed to allow families to remain eligible for SSI and Medicaid benefits while caring for their severely disabled child at home -- only if home care is less expensive than hospital care. Parents would no longer have to choose between financial instability and the location of their child. For families like the Mulligans, this small change in the income deeming laws will permit their daughter Kaleigh to stay at home without risking financial ruin.

I greatly appreciate this opportunity to testify before the Subcommittee on H.R. 1525 which is so important to families with severely disabled children. I have great respect and admiration for the work that the Chairman and Members of the Subcommittee have done to guard the rights and enhance the resources of the disabled and their families. I also wish to thank Mrs. Kathleen Mulligan of my district in Methuen, Massachusetts, whose dedication and perseverance has been an inspiration to all individuals that believe that one person can make a difference.

Statement of Raymond Avrutis, recipient of Social Security Disability Income, before the House Human Resources Subcommittee hearing on Supplemental Security Income outreach programs. May 30, 1989.

America's mentally ill have resources available to them of which they are unaware. A reading of the White House Domestic Policy Council's Up From Dependency, released in 1988, combined with other sources such as Programs of HUD 1988/89, and the work of Sen. Pete V. Domenici (R-NM), reveals no fewer than 60 government programs from which mentally ill people may receive benefits.

Programs include housing, cash payments, health care, food assistance, service programs, job training, 20 programs for the homeless in the McKinney Act, and miscellaneous programs. No one source contains the major laws, rules, regulations and interpretations necessary to write a book, tentatively titled Government Benefits for the Mentally Ill: A Guide to 60 Programs.

The federal government should spend whatever amount of money it takes to publish, between hard covers, a single publication, an easy to understand one for a change, Uncle Sam, that tells America how to get this kind of help. I would like to write this book. I am a non-violent, functioning schizophrenic who was institutionalized between ages 12 and 15 because he meowed and claimed he was a cat. I was fortunate enough to attend an alternative high school, and was Senior Class President at American U. in 1970, age 22. My book, How to Collect Unemployment Benefits: Complete Information for All 50 States, was published twice. I am finishing my third master's degree.

The Washington Post's health section estimated on May 9 that one in every three Americans will become mentally ill, if only for a brief time, during their lifetimes. To help mentally ill individuals cope, there exists an army of not less than 229,000 social workers, clinical psychologists and psychiatrists. These health care professionals could read and interpret benefit rights to clients who could benefit from such information. Additionally, friends and relatives of the mentally ill could buy such a book and could help their people apply for and receive their rightful entitlements.

If Ravi Batra, author of The Great Depression of 1990, is correct and the world will experience a catastrophic economic decline soon, such a book would serve two purposes: First, to tell the Office of Management and Budget where programs could be cut and, secondly, to inform the mentally ill and their friends of programs to lobby for.

The government programs to be discussed are not solely for those with psychological difficulties. Many other handicapped persons, as well as some people who are just plain poor, may receive benefits. And benefits received keep money flowing in the economy, and help keep other people working.

Landlords and utility companies should be pleased at cash programs people may benefit from. Farmers, middlemen and grocery stores should enjoy the food programs. Home builders should accommodate the housing programs. Doctors and nurses should be pleased with Medicaid and Medicare. And so on.

Ideally, every ward of every mental hospital would have at least one copy of a book to tell people what help and assistance they could expect from the "outside world." The federal government, which has numerous publications explaining the income tax laws and a staff of people to dispense (often wrong) information, should do right by the mentally ill, and tell them what their benefit rights are.

The next two pages are my Table of Contents from a 49-page book outline, Government Benefits for the Mentally Ill. I am seeking a publisher.

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*This is a term paper as well as a book outline. Therefore, both Roman and Arabic numerals are used. The finished book manuscript will use only Arabic numerals, in the upper right hand corner.

**According to The Washington Post, this appropriation consists of 20 programs, some of which are funded at very low levels.

Other Government Programs that Help the Mentally Ill

Program #/Subject

I. Cash Programs

37 Supplemental Security Income (SSI)*
38 Social Security Disability Income (SSDI)
39 General Assistance (welfare)
40 Pensions for War-time Veterans**

II. Food Programs

41 Food Stamps
42 Temporary Emergency Food Assistance Program
43 Food Donations to Charitable Institutions

III. Health Programs

44 Medicaid
45 Medicare (for SSI recipients who have been on the rolls 24 months or more)
46 Community Health Care Centers
47 Veterans Health Care (non-service connected)**

IV. Service Programs

48 Community Services Block Grant
49 Legal Aid (Legal Services Corporation)
50 Family Planning Services

V. Employment Programs

51 Training Services for the Disadvantaged (JTPA II-A)
52 Summer Youth Employment Program (JTPA II-B)***
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VI. Other Low Income Grant Programs****
54 Vocational Rehabilitation Services
55 Vocational Education Grants to States
56 Health Careers Opportunity Program
57 Rural Self-Help Technical Assistance
58 Employment Services and Job Training
59 Graduate and Professional Fellowships
60 Exceptional Financial Need Scholarships

*On May 30, 1989, the House Subcommittee on Human Resources, chaired by Rep. Thomas J. Downey (D-NY), will hold hearings to decide, in part, "...should Congress pass legislation requiring /the Social Security Administration/ to conduct specific, ongoing outreach activities."

**Veterans benefits in the United States are not codified.

***About 100,000 new cases of schizophrenia occur yearly, mostly among adolescents and young adults.

****These programs receive very small funding. But as they become known, perhaps people will ask for increased authorizations.

STATEMENT OF MR. ROBERT K. DRESING,
PRESIDENT AND CHIEF EXECUTIVE OFFICER

CYSTIC FIBROSIS FOUNDATION
WASHINGTON, D.C.

Mr. Chairman and Members of the Subcommittee:

My name is Robert K. Dresing and I am president of the Cystic Fibrosis Foundation (CFF). I submit this statement on behalf of the thousands of children and young adults with cystic fibrosis (CF), including my own 22-year-old son, Rob.

Those of us whose lives are affected by this fatal, genetic disease are entering the 1990's with optimism. The news from scientists is good: CF research is moving rapidly toward the knowledge that will allow our children to survive into the next century.

However, our efforts to increase the length and quality of lives for all of the children with CF may be undermined by the lack of appropriate and sufficient public assistance for the most disadvantaged of these children. Therefore, I thank you for this opportunity to highlight some of the problems needy children and young adults with CF have in obtaining Supplemental Security Income (SSI) through the Social Security Administration (SSA), and ask for your support in changing this situation.

The Foundation strongly supports H.R. 868, "The SSI Disabled and Blind Children Act of 1989." We would like to thank you, Chairman Downey and Mr. Matsui, for introducing this comprehensive bill addressing many of the inadequacies of the SSI program. This bill shows great promise in bringing SSI benefits to poor, disabled children. For a number of children with CF, this bill offers what may be the only way to enable their impoverished families to obtain vital medical care and meet their daily medical needs.

Several provisions of this bill are particularly vital to the improvement of the SSI program for people with CF. With these changes, more eligible, needy children and young adults will receive the comprehensive evaluation for SSI benefits that they desperately need. Therefore, the Cystic Fibrosis Foundation respectfully suggests the following changes to enhance the SSI program:

1) ALLOW FOR INDIVIDUAL FUNCTIONAL ASSESSMENT OF CHILDREN APPLYING FOR SSI

Currently, many children with CF who apply for SSI are turned down because they do not meet the restrictive medical listings. Cystic fibrosis is a fatal, genetic disease. The symptoms of this disease include thick, sticky mucus secretions that clog the lungs and gastrointestinal system, impairing breathing and digestion. The mucus can lead to recurrent lung infections and malnutrition. Other severe complications of cystic fibrosis can include diabetes and cardiac problems. Separately, these symptoms may not meet the requirements for a severe disability. However, when all aspects of the disease are viewed together, the combination can be extremely disabling.

Despite the devastating effect of CF on a child's daily life and the continuous medical treatments that may be necessary, a child is ineligible for benefits if his breathing impairments are not severe enough to render him totally disabled according to the respiratory category in the Listing of Impairments. Often, the effects of the disease on other parts of the child's body are not considered, since the child's total functional capacity is not evaluated.

Relying solely on the medical listings to determine a child's eligibility without a functional assessment subjects children to much stricter eligibility guidelines than adults. Adults are evaluated by their ability to work or function in society. However, children do not receive this individual functional assessment. This assessment would enable SSA to fully review the capabilities of children in a manner comparable to the evaluation for adults.

The sole use of narrow medical listings for eligibility also does not take into consideration the effect of multiple impairments on the person's ability to function. Consider, for example, the case of a young girl who has been denied benefits despite having CF, diabetes, asthma, and scoliosis. Viewed separately, none of her disabilities met the Listings of Impairments. Yet, the overall impact of this devastating combination on her life was not evaluated, and she was denied SSI benefits.

2) **REQUIRE UPDATES OF LISTINGS OF IMPAIRMENTS TO ILLUSTRATE CURRENT MEDICAL KNOWLEDGE**

Updating the Listings of Impairments to consider today's medical knowledge would enable a more accurate medical assessment of children with CF. With the changes in understanding and treating CF, many people with this disease are now living into their twenties and beyond, when once they only had a life expectancy of five years. Improved treatments and medical assessments have changed the lives of many people with this disease. The medical listings need to reflect this state-of-the-art knowledge of and treatment for CF.

The Social Security Administration has taken some steps to ensure that the respiratory category for the Listings of Impairments are improved. One of our CF specialists participated in a review committee under the SSA's guidance to revise these listings; this committee's work is currently being reviewed by the SSA. We would like to encourage the SSA to publish these suggestions in full as they do reflect more current and state-of-the-art methods of assessing the lung function and overall health of children with CF. These changes to the listings would help to ensure that children with CF would receive a more accurate and complete functional assessment.

The Cystic Fibrosis Foundation is striving to provide a better future for people with CF through improved medical care and better research. Without ongoing support from the Congress for vital programs such as SSI, our work to enhance the future for all people with CF may be undermined.

In summary, we support the use of functional assessments by the Social Security Administration to determine a child's eligibility for SSI. In addition, we would like to see the Listings of Impairments revised and updated, reflecting a state-of-the-art medical understanding of CF and other diseases.

We strongly urge Congress to support H.R. 868 to revitalize the SSI program, enabling SSA to assist those needy, disabled children for whom the program was intended. The lives of thousands of people with CF depend on your continuing investment in SSI. Accurate medical information about CF and appropriate evaluation of children with CF will enable eligible children to receive benefits in a more timely fashion. We thank you, Chairman Downey and Mr. Matsui, for your support for the SSI program.

TESTIMONY BY
FLORENCE M. RICE
PRESIDENT
HARLEM CONSUMER EDUCATION COUNCIL, INC.

Good afternoon, my name is Florence M. Rice, President of the Harlem Consumer Education Council in New York City. I am pleased to come before you to discuss the need for improvements in the SSI program. I will direct my remarks to the reasons that older Americans, particularly African-Americans do not apply for SSI.

We older African-Americans came up in a whole different era in which a sense of pride was drilled into us by our parents--hard work was the order of the day rather than seeking handouts. Yes, we were raised proud and independent--and because we were, we believed that we did not have to bare our souls before the world. This may be a misguided concept in this day and time, but the two things that most of us have left are the pride and that spirit of self-reliance--and we guard them fiercely.

That is why so many of us resist applying for SSI. SSI to us is like welfare--not being able to take care of yourself. And if we don't feel bad enough about that, then the humiliating process the SSI puts us through reinforces the feeling. In order to qualify, we must remove the source of the meager assets that we have worked so hard to accumulate, that we paid taxes on, that we have saved in the event that we must cope with a catastrophic illness, or to provide a decent burial or to give us the comfort that we deserve in our old age. They force us to reduce or eliminate those assets in order to qualify, but before we still can qualify, we must prove where those assets have come from and how we got rid of them.

One lady told me of her experience: She had told the interviewer that the had $10,000 in the bank. She was then told that she would have to "spend it down." After she had done so, the interviewer wanted to know what she had "spent it down" on and not only demanded receipts (they "receipt" us to death!) but also her bankbook to see how she accumulated those monies in the first place! Nobody gives you a darn thing, but when you get it, everybody wants to know how you got it! What would have been the alternative in this case? She should have kept quiet about her assets; she should have lied. Our society forces us to be cheats and liars. If you do not lie in today's society, you do not get anywhere. But just as the senior in my story, we do not lie, we tell the truth! Poor old people tell the truth because that is the way we were raised--to respect authority and to be honest. And when we do tell the truth about our circumstances, we get nothing--not only in SSI, but in welfare too!

Take my situation as an example: I receive approximately $317 per month from Social Security and pay $244.19 per month for rent, which leaves me with a balance of $63. But when one tells that to the bureaucrats at HEAP or SSI, they don't believe you! They want to know "how do you live?" How do I live? I am fortunate enough to have a good daughter and son-in-law, grandchildren and an "adopted" son who help me out when I call on them. Others are not that fortunate and so they are forced to be without--without sufficient food, warm clothing, money to pay their bills or to purchase the small comforts of life. And yet with all that hardship staring them in the face, they would rather suffer than put themselves through the humiliation of publicly explaining all that they must endure to get by.

And why should they have to? In Sweden, they give support to their elderly, but they do it with caring and sensitivity. They do not, as we do, intimidate their elderly from the onset of the SSI application process. Those who are charged with the provision of services to the public do not know how to treat others so that they can retain a sense of dignity and worth. In the interview process, they strip you like a banana! They leave no stone unturned to assure themselves that you are not a cheat. And we are not the cheats, we are the cheated--cheated out a living wage in our earlier years, exploited by employers who found all sorts of excuses to keep from paying us, often paying us off in left over food and cast-off clothing. Many of us really need SSI because we

worked as domestics and either came into the Social Security system too late to accumulate sufficient reserves or worked for very low wages or for employers who conveniently "forgot" to make Social Security contributions on our behalf.

Yes, we African-Americans feel cheated. We came into the world poor and this society wants to make damn sure that we go out the same way!

We don't need programs dreamed up by Ph.D.'s who don't understand reality. We need programs that recognize our needs and meet them while helping us to maintain some dignity and pride.

There must be a change in the demands placed upon us and the way we are handled by SSI. We do not expect to be spoon-fed, but we do demand respect. They owe us that! If you want to seek us out and include us in SSI, then you must change your tactics, because we grouchy, forgetful, poor, yet sensitive and proud older people cannot change ours!

STATE OF MINNESOTA
DEPARTMENT OF HUMAN SERVICES
Human Services Building
444 Lafayette Road
St. Paul, Minnesota 55155-3848

May 26, 1989

The Honorable Thomas J. Downey
Acting Chairman
Subcommittee on Human Resources
Committee on Ways and Means
United States House of Representatives
1102 Longworth House Office Building
Washington, D.C. 20515

Dear Representative Downey:

I am writing in response to the announcement that the Subcommittee on Human Resources is soliciting comments regarding the Supplemental Security Income (SSI) Program. I do not wish to testify so I am submitting this written statement on behalf of the Minnesota Department of Human Services.

1. Should children receive individual functional assessments?

   It seems imperative that children do receive individual functional assessments if an accurate determination of disability is going to be made. In Minnesota, we have three home and community based service waivers, as well as the TEFRA 134 Option for Certain Disabled Children. Each of the waivers has an individual assessment, and a special assessment was specifically developed to implement the TEFRA Option. Part of the TEFRA Option requires that the child be certified as disabled. Our State Medical Review Team (SMRT) uses the same criteria that is used by the Social Security Administration. However, in order to certify children as disabled, we have adjusted the criteria so that it relates specifically to children. As an example, we do not determine whether or not the child can be employed, but rather, consider if the child can attend school and do other activities that children of the same age do without extraordinary assistance. We would be willing to share our assessment criteria and forms with the Subcommittee on Human Resources if the committee feels that they may be of some help.

2. Should Congress require SSA to use pediatricians to perform the assessments?

   Assessments need to be performed by individuals who have expertise in the specific population. Certainly a pediatrician needs to be a part of the assessment. In addition, often times the presenting problem is so rare, that there may only be a very few professionals who have had experience

with such a diagnosis. Therefore, it is also often appropriate to have the expertise of the specialty professional. The professional may not necessarily be a medical doctor.

3. If disabled children can be cared for appropriately at home, at a lower cost than in institutions, should Congress allow these children to received Medicaid benefits and the SSI personal needs allowance of $30 per month?

Minnesota firmly believes in providing cost-effective home and community based services, especially for children. However, providing Medicaid eligibility will not necessarily allow children to be served in the community. Under current regulations, states may choose whether or not they will provide optional Medicaid services. States also choose the amount of services that will be reimbursed by Medicaid. Many states do not provide the optional services or do not provide service amounts adequate to meet the needs of disabled children in the community. In addition, current Medicaid regulations do not allow nursing or personal care services to be provided anywhere but within the walls of the home of an individual. Many disabled children need nursing or personal care in order to attend outside activities such as school, church, or scouting. Unless these regulations are changed, children who receive their care in the community will only be able to receive home bound education, never go to church, or participate in recreational activities. Without change in the Medicaid regulations, these children would be prisoners in their own homes. They would have much more opportunity to participate in their community if they were residents of institutions. Nursing facilities and Intermediate Care facilities for Persons With Mental Retardation are required to provide individuals with opportunities to participate in educational, religious and recreational activities outside of the facility. The facilities are responsible for assuring that individuals who wish to participate in outside activities are able to do so, and that appropriate medical cares are provide while that individual is away from the facility. Appropriate facility staff must accompany the individual to provide those cares while away from the facility. The Medicaid regulations, that do not allow persons who need nursing or personal care services to receive those services outside of their home, are discriminatory and in violation of the Handicapped Act.

Our experience indicates that many children with disabilities can be served at home at no greater cost than in institutions. Cost neutrality and parental choice, not cost savings, should be the standards for comparing home and institutional care of these children.

4. Should the childhood listings of impairments be updated?

Yes. One example is the category of catastrophic congenital abnormalies or disease, 110.08, as written, precludes children with Down syndrome. A

second example is the classification of Mental and Emotional Impairments which need elaboration.

5. Should children with severe genetic and congenital diseases be presumed disabled until such time as medical professionals can test them for disability?

   We urge that children with severe genetic and congenital diseases should be presumed disabled until they can be properly assessed and diagnosed. Children suffering from the effects of maternal chemical abuse or AIDS should be included in this group.

   This decision or presumption could be based on the available medical evidence, plus the data from nationally recognized assessment instruments such as the Bayley and the Denver Developmental Screening Test. If these children are certified as disabled for medical assistance, in some cases corrective work could be done, or begun earlier, that would reduce the extent of their disability.

6. In the case of adults with disabilities, SSI payments should be so structured as to not discriminate against those who live in the household of others, or those who live in their own home. Corrections and adjustments, such as averaging SSI benefit checks to avoid loss of benefits in extra check months, and to recognize changing costs of living, are recommended for review and appropriate action.

7. Finally, it is recommended that the Subcommittee consider making full SSI benefits available for eligible children with disabilities being cared for at home, without regard to parental income or resources, as a cash subsidy. In Minnesota, the Family Subsidy Program currently serves some 375 families with children having developmental disabilities. The average payment of $236 per month for each child to prevent out-of-home placement is a cost-effective program. The program is limited by funding availability, with many families on a waiting list. Federal provision of a modest cash-grant subsidy for families of all eligible children would be both humane and cost-effective.

I commend the Subcommittee for taking the initiative in reviewing SSI standards and procedures. It is an opportunity to make a good program better. We appreciate the opportunity to contribute to that effort.

Sincerely,

Mary Kennedy

Mary Kennedy, Director
Health Care Management

Testimony By
Carmela G. Lacayo
President and Chief Executive Officer
Asociacion Nacional Pro Personas Mayores
(National Association for Hispanic Elderly)

Mr Chairman and Members of the Human Resources Subcommittee, the Asociacion Nacional Pro Personas Mayores welcomes the opportunity to submit this statement for the hearing record on proposals to improve Supplemental Security Income (SSI).

SSI is of primary importance for the Asociacion because aged Hispanics have one of the highest poverty rates among older Americans. In 1987, 27.4 percent of all Hispanics 65 years of age or older were poor.

Individuals 65 or older were considered poor in 1987 under the U.S. Census Bureau definition if their annual income was below $5,447 ($6,872 for an elderly couple). This translates to just $105 per week ($132 per week for an aged couple) to pay for housing, food, medical care, transportation, clothing, and other everyday necessities.

Older Hispanics are more than two and one-half times as likely to be poor as elderly Whites: 27.4 percent vs. 10.1 percent in 1987. The situation has deteriorated. Poverty among older Whites declined from 10.7 percent in 1986 to 10.1 percent in 1987. However, the poverty rate rose significantly for aged Hispanics during this same period, from 22.5 percent in 1986 to 27.4 percent in 1987.

The harsh reality is that older Hispanics are treading water in an economic rapids that threatens to drown them. The aged Hispanic poverty rate in 1987 was, for all practical purposes, the same as it was in 1976: 27.4 percent in 1987 compared to 27.7 percent in 1976.

Poverty is especially widespread among elderly Hispanics who live alone or with nonrelatives. In 1986, 55.3 percent of all unrelated elderly Hispanic women and 37.2 percent of all aged unrelated Hispanic men were poor.

Importance of SSI for Older Hispanics

Approximately one out of every five (20.2 percent) older Hispanics received SSI in 1986. This represented the highest proportion among major elderly groups. For example, aged Hispanics were nearly five times as likely to receive SSI as older Whites: 20.2 percent vs. 4.3 percent.

Percent of Persons 65 Years of Age or Older Receiving SSI in 1986

All Races	White	Black	Hispanics
5.7%	4.3%	19.0%	20.2%

Source:

Unpublished data from the March 1987 Current Population Survey
U.S. Dept. of Commerce
Bureau of the Census

SSI also constitutes a much larger share of aged Hispanics' income than for most other elderly groups. In 1986, SSI represented 6.4 percent of the elderly Hispanics' total income, compared to 0.9 percent for all other older Americans, 0.6 percent for Whites 65 or older, and 5.3 percent for aged Blacks.

SSI Legislation

These facts underscore the importance of strengthening SSI. As a practical matter, the poverty rate for older Hispanics is not likely to be reduced appreciably in the next few years unless SSI is significantly improved.

Two major sources of income for elderly Hispanics -- Social Security and SSI -- have, at best, only kept pace with rising prices. However, cost-of-living adjustments (COLAs) for Social

Security and SSI -- valuable as they are -- do not enable older poor persons to escape from poverty. Moreover, aged Hispanics frequently find themselves at or near the bottom of the economic totem pole in receiving other sources of income which can enable them to move off the poverty rolls. For example, elderly Whites are more than twice as likely to receive retirement income from a pension or an annuity as older Hispanics: 32.1 percent vs. 16.1 percent in 1986. Nearly seven out of ten (69.8 percent) aged Whites receive interest income, compared to only three out of ten (31.2 percent) elderly Hispanics. Moreover, a large percentage of older Hispanics with interest income receive only a paltry amount.

For these reasons, the Asociacion believes that SSI benefits must be increased above and beyond the cost of living. A failure to do so will simply leave many older Hispanics and other low-income older Americans on an economic treadmill. H.R. 361 and H.R. 866 (SSI Benefit Improvement Amendments of 1989) are, in the judgment of the Asociacion, two of the most important measures introduced during this Congress because they would establish a timetable for eliminating the ugly cancer of poverty in old age. Both bills would increase the federal SSI maximum payment over a three-year period until it equals the poverty line by 1992. H.R. 866 includes other provisions, which we shall discuss later.

Need for an Income Strategy

The Asociacion recognizes fully that the budget deficit will make it extremely difficult for this legislation to be enacted soon. However, we reaffirm that it is essential for Congress to approve SSI benefit increases which exceed the cost of living.

The harsh reality is that our nation does not now have an income strategy for Social Security or SSI except for annual COLAs. In fact, Social Security beneficiaries have not received an increase above the COLA since that mechanism first became effective in 1975. SSI recipients have had only one benefit hike exceeding the cost of living since the program became operational in 1974, but this was linked to a six-month delay in the Social Security COLA under the 1983 Social Security Amendments. Experts have estimated that this change cost Social Security beneficiaries -- many of whom were low-income older Americans -- about $4.3 billion in 1986.

Therefore, the Asociacion renews its recommendation that the SSI income standards should be raised, as soon as possible, to a level to abolish poverty once and for all for older Americans. It will probably be necessary -- at least initially -- to implement this goal with modest adjustments above the cost of living because of budgetary considerations. However, this should not deter our nation from implementing this objective.

The Asociacion wishes to respond frontally to those who say that only technical SSI changes can be enacted now because of the budget deficit. Modest adjustments in SSI benefits which exceed the cost of living can still be approved during this austere period by having the regular COLA and then a delayed benefit hike. Numerous other alternatives exist as well.

Moreover, we could easily finance SSI benefit raises above the regular cost of living by either reducing or eliminating the monumental waste at the Pentagon. Similarly, our nation could abolish poverty for older Americans by reordering our priorities. For example, we could eliminate poverty for the elderly and disabled for the cost of two nuclear aircraft carriers, and with money to spare.

It may take our nation a while before we take these necessary actions. In the meantime, though, it is crucial to adopt an income strategy which provides increased purchasing power for

those on SSI as soon as possible. Time is not on the side of older Americans. It is crucial that we act now to close the gap between poverty and the current SSI benefits.

Update Countable Resource Limitation

Other changes are also needed to improve SSI. One high priority item is to increase the SSI countable resource ceilings. Currently, the limitation is $2,000 for a qualifying single person and $3,000 for an eligible couple.

Inflation has greatly eroded these ceilings, even with the recent incremental adjustments. This has produced a bizarre effect where many older Americans who would otherwise qualify for SSI are declared ineligible because they are considered "asset rich."

H.R. 360 and H.R. 866 would raise the SSI countable resource limits from $2,000 to $4,200 for a qualifying individual and from $3,000 to $6,300 for an eligible couple in 1990, with automatic adjustments thereafter. If this measure would be too costly under the present budget, it could be scaled back by incremental adjustments.

Outreach

A major outreach effort is needed to enroll eligible persons in SSI. The Ford Foundation report on "The Common Good" reported, "About one-half of those eligible for SSI benefits do not even participate in the program." The Asociacion has discovered that numerous older Hispanics do not even know that SSI exists.

The failure to enroll for SSI can have spillover effects for low-income older persons who encounter difficulty in paying for their health care costs. For instance, the recent Ford Foundation report pointed out, "More than half of the elderly poor cannot get financial help with the unreimbursed costs of Medicare treatment because they are not on SSI rolls and thus have trouble meeting Medicaid eligibility rules."

The Asociacion strongly supports the provision in H.R. 866 to direct the Social Security Administration to conduct an ongoing outreach program to provide information about the availability of SSI benefits to low-income aged, blind or disabled persons. We urge the Subcommittee to approve this proposal.

Medicaid

Finally, the Asociacion favors the measure in H.R. 866 to consider persons otherwise eligible for SSI benefits, except for the in-kind assistance rule, to be eligible for SSI for Medicaid purposes. Currently, the federal SSI benefit standard is reduced by one-third when elderly persons reside in the household of another and receive in-kind maintenance and support. This existing provision often discourages families from helping other relatives and causes some aged Hispanics and other older Americans to be prematurely or unnecessarily institutionalized.

H.R. 866 would help to remove the disincentive under present law, while providing valuable protection from medical costs.

Conclusion

In conclusion, the Asociacion commends the Human Resources Subcommittee for holding this hearing. We further urge the Subcommittee to approve the recommendations which we have included in our written testimony.

The Asociacion fully realizes that the subcommittee will need to prioritize proposals because of cost considerations. We would urge as our number one legislative goal the enactment of an SSI increase in addition to the regular COLA.

The paramount need for aged Hispanics and other low-income older Americans is additional income. There is simply no suitable substitute for this basic need.

We look forward to working with the Subcommittee for the enactment of this recommendation and other proposals to improve and perfect SSI.

STATEMENT OF THE NATIONAL ASSOCIATION OF DISABILITY EXAMINERS

ON

PROPOSALS TO IMPROVE THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

prepared by

Karen Gunter, NADE President

and

Martha Marshall, NADE Legislative Committtee Chair

On behalf of the officers and members of the National Association of Disability Examiners (NADE) we wish to take this opportunity to comment on the proposals to improve the Supplemental Security Income (SSI) Program.

NADE is a professional organization whose members are involved in all aspects of disability evaluation. The majority of our than 2100 members are individuals who are directly involved in the documenation and adjudication of claims filed under the Social Security and/or Supplemental Security Income disability programs. It is this backgroung which we feel gives us a unique perspective on the disability program and the ability to assess the impact of change, not only on the claimant/beneficiary but on the disability program itself and on those whose job it is to implement change.

We are not primarily claimant advocates, although we are deeply concerned about the applicants we serve. Nor are we proponents of maintaining the status quo. Rather, we support a humane, equitable and consistent nationally uniform disability program and we believe that any changes in this program must be made carefully.

We do not support legislation which would require the Social Security Administration to conduct additional outreach activities. SSA is already conducting a number of such activites. However, there may be a question of whether these messages are reaching their intended audience. Before initiating more outreach activity we propose that SSA first conduct a study to determine the effectiveness of what is currently being done. It would seem to serve no useful purpose at this time to add to the amount of information which is being disseminated by SSA if that information is not reaching the intended population.

With regard to disabled children, we strongly support updating the childhood Listings of Impairments. Revisions to the childhood Listings have been "in progress" for several years, These revisions are long overdue. The Listings should be constantly updated to acknowledge and accommodate changes in the field of children's medicine.

Functional assessments (or assessments of the child's ability to perform age-appropriate activities) are already incorporated into many of the current Listings. These types of assessments should be included in the revised Listings and applied to as many impairments as possible. In addition, each claim must be evaluated on an individual, case-by-case basis (It should be noted that this will require Congress and SSA to provide adequate resources in terms of clear, consistent guidelines, training and appropriate staffing levels.)

We do not support changing the basic defination of disability for SSI children's claims. There are many children who are in need of medical care but who are not ill enough to be eligible for SSI benefits under the current guidelines. However, to change the definition of disability, to label a child "disabled" at a young age primarily so he or she can receive medical care is an injustice--both to the child and to society as a whole.

We believe that pediatricians should be involved as appropriate, and when possible, in the evaluation of children's claims. However, we strongly oppose any requirements to use pediatricians exclusively in such evaluations. Not only might State Agencies (particularly the smaller agencies) have difficulty obtaining pediatric resources, this requirement would seem to exclude other specialists (psychologists, cardiologists, orthopods, etc.) when their specialities might, in fact, be more appropriate.

Presuming disability for children with specific severe genetic or congenital impairments, established by appropriate diagnostic procedures, would appear to be humane approach, consistent with the concept of "disability". To deny a claim, not because the impairment does not meet or equal the medical Listings, but because the child is too young to test, does not seem appropriate. We are concerned, however, that it will be impossible to evaluate medical improvement in these cases. Therefore, if this proposal is implemented, we recomment that these claims be exempted from the medical improvement standard until the child is old enough to be medically evaluated. (once the child has been continued based on medical criteria, subsequent reviews would be subject to the medical improvement standard)

In summary, we believe that additional outreach activities by SSA should not be required at this time; that the childhood Listings should be revised and updated regularly (and such revision is long overdue); that "functional assessments" in SSI children's claims should be, as they currently are, assessments of the child's growth and development and ability to perform age-appropriate activites; that pediatricians should be used in the evaluation of these claims when appropriate but this involvement should not be required; that the basic definition of "disability" should not be changed and the if presumption of disability is to be made based on the presence of the severe genetic or congenital impairment that these claims should be exempted from the medical improvement standard until the claim has been medically documented.

Thank you for your consideration of NADE's comments.

STATEMENT BY
SAMUEL J. SIMMONS
PRESIDENT
NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC.

Mr. Chairman and Members of the Human Resources Subcommittee, the National Caucus and Center on Black Aged, (NCBA) welcomes the opportunity to submit testimony at this hearing on proposals to improve Supplemental Security Income. At the outset, NCBA wishes to commend the Subcommittee for holding this timely hearing.

NCBA collaborated with the House Committee on Aging and the Congressional Black Caucus in 1986 to conduct a series of hearings and issue forums in eight major cities with a large aged Black population. More than 100 witnesses -- including senior citizens, program administrators, government officials, respected leaders in the field of aging, and others -- testified at the six issue forums and three field hearings.

Their message was brief but blunt. Inadequate income in retirement is the number one dilemma for older Blacks. No other problem looms as large as the retirement income crisis which already affects many aged Blacks and threatens to engulf more. Inadequate income is a root cause for virtually every problem confronting elderly Blacks, whether it is poor health, an inappropriate diet, dilapidated housing or something else.

A. Nature of Problem

Poverty is still a very widespread problem for older Americans, despite major improvements in the overall economic well-being of elderly persons during the past 20 years. Most of these advances occurred, though, during the late 1960's and early 1970's when Congress enacted major increases in Social Security, the economic mainstay for the vast majority of older Americans. During the past decade, the elderly have found themselves in virtually an economic quagmire.

Nearly 3.5 million persons 65 years of age or older were poor in 1987 -- about one out of every eight (12.2 percent) older Americans. The elderly have the highest poverty rate among adult groups. Only children and young persons under the age of 22 have a higher poverty rate than individuals 65 or older.

Poverty is especially widespread among sizeable segments of the elderly population, particularly aged minorities, women, persons living alone or with nonrelatives, and the very old (individuals 85 or older). For example, 19.2 percent of all Americans 85 or older were poor in 1987 -- virtually the same rate as for persons under 22 years of age (19.7 percent).

B. Poverty Among Aged Blacks

Poverty is exceptionally high among aged minorities. In fact, it is typically two to three times as great as for elderly Whites.

In 1987, one out of every three Blacks was mired in poverty. The number of poor aged Blacks grew by 86,000, from 722,000 in 1986 to 808,000 in 1987. Moreover, the aged Black poverty rate rose from 31.0 percent in 1986 to 33.9 percent in 1987.

The bottom line is that the 1987 poverty rate for older Blacks was exactly the same as it was in 1978. Consequently, aged Blacks have not made any progress in escaping from poverty's vicelike grip.

Elderly Blacks living alone or with nonrelatives are among the most economically deprived groups in our entire society. In 1987, 62.8 percent of all older Black females living alone or with nonrelatives were poor. This figure was 42.2 percent for similarly situated aged Black males.

C. Supplemental Security Income

Congress enacted the Supplemental Security Income (SSI) program in 1972 to build a federal floor under the incomes of aged, blind and disabled persons. Currently, the maximum federal SSI payment is $368 a month (less than $13 a day) for a qualifying aged individual and $553 a month for an eligible elderly couple (approximately $18 a day). In 1989, the maximum federal SSI payment will represent about 74 percent of the projected poverty threshold for a single aged person and approximately 83 percent for a couple.

NCBA strongly believes that the most effective means to improve the economic well-being of older Americans is to strengthen SSI because it serves low-income qualifying individuals. SSI is especially important for aged Blacks because one out of five (19.0 percent) Blacks 65 years or older receives SSI. In fact, SSI represents about nine times as much of elderly Blacks' aggregate income as it does for older Whites: 5.3 percent of total income vs. 0.6 percent.

D. Increase SSI Benefit Standard to Poverty Line

These facts underscore the critical need to increase SSI benefits. NCBA's number one legislative objective is to raise the federal SSI benefit standard to at least the poverty line, and preferably above it.

For these reasons, NCBA strongly supports the provisions in H.R. 361 and H.R. 866 which would increase the federal SSI maximum payment in increments over a three-year period until it would equal the poverty threshold by 1992.

Our nation has not had an effective income strategy to overcome poverty for older Americans since the 1970's. NCBA cannot understate the importance of launching an income strategy by enacting concrete increases in SSI benefits. Virtually every respected authority -- such as the Commonwealth Fund, the Villers Foundation, and the Ford Foundation -- believe that SSI benefits must be raised.

However, the biggest impediments to implement this objective seem to be political and budgetary. Some so-called authorities now believe that a benefit increase is impossible because of the deficit. Consequently, they are arguing that basically only technical changes can be made.

NCBA fully realizes the magnitude of our budget deficit. However, we do not accept the notion that only perfecting changes can be enacted for SSI. We believe that it is absolutely indispensable to have a benefit increase. We recognize that it may be necessary to have a modest increase because of budget considerations. We are also fully aware that the objectives in H.R. 361 and H.R. 866 may take several or even many years to implement.

But, it is important to start the task now, even if the first step is very modest -- such as a $2 or $5 monthly increase above the projected cost-of-living adjustment (COLA) for 1990. Any SSI increase above the normal COLA, no matter how small, will close the poverty gap. Moreover, any increase above inflation provides a higher base for application of future COLAs. A benefit increase is needed now because time is working against elderly Blacks and other low-income older Americans.

NCBA wishes to stress that a boost in SSI benefits can be achieved even under austere budget assumptions. One option is to have a regular COLA and a delayed subsequent benefit hike. Other alternatives exist as well.

NCBA urges the Subcommittee to make a concerted attempt to enact a benefit increase above the COLA. We know of many situations (e.g., Social Security increases and numerous others)

where so-called experts said that certain measures were not legislatively attainable, and they were later proved wrong. An SSI benefit increase can be achieved -- even in today's budgetary climate -- if the proposal is carefully crafted and appropriately backed by this Subcommittee and the organizations representing the SSI constituency.

E. Improved Outreach

Improved outreach is also needed because a significant percentage of the elderly poor do not receive SSI. In 1986, for example, the number of aged persons on the SSI rolls represented just 58 percent of the entire elderly population. At that time, 3,477,000 older Americans were poor. But, only 2,016,000 persons 65 years of age or older received SSI.

One important reason is that many older Americans have either insufficient or erroneous knowledge concerning SSI requirements and benefits. This is particularly true for older minorities, especially those with limited English-speaking ability. A Social Security study in 1983, for example, revealed that 45 percent of eligible persons who did not participate in SSI were unaware of its existence.

NCBA supports a provision in H.R. 866, directing the Social Security Administration to conduct an ongoing outreach program. H.R. 866 would also call upon the Social Security Administration to enter into cooperative agreements with other government agencies and nonprofit organizations serving SSI recipients to bolster outreach activities.

F. Update Countable Asset Limitations

The SSI countable resource limitations -- currently $2,000 for a qualifying individual and $3,000 for an elderly couple -- need to be updated. In real dollar terms, the resource levels have been almost cut in half by inflation. In 1974, the countable resource limits amounted to $1,500 for a qualifying individual and $2,250 for an eligible couple.

The outdated asset ceilings, it is estimated, prevent more than 100,000 low-income older Americans, who would otherwise qualify for SSI, from receiving benefits.

NCBA supports H.R. 360 and a measure in H.R. 866 to raise the SSI countable resource ceiling from $2,000 to $4,000 for qualifying individuals and from $3,000 to $6,300 for eligible couples, with automatic adjustments for inflation in the future.

G. One-Third Reduction

Another major concern for aged and disabled Americans is the existing SSI provision which causes a one-third reduction in the basic SSI benefit standard when an eligible individual lives in the household of another for a month or more and receives in-kind maintenance and support. This measure can have an unintended effect of discouraging families from helping their parents or grandparents. Moreover, it may cause some low-income elderly persons to be prematurely or unnecessarily institutionalized at a higher cost than would be the case if the one-third reduction did not apply to them.

NCBA supports two features in H.R. 866, which we consider to be especially innovative in easing the burden of the one-third reduction provision. First, all in-kind assistance would be counted according to its actual value but not in excess of one-third of the federal SSI benefit standard. Second, persons otherwise eligible for SSI, except for the one-third reduction provision, would be deemed eligible for SSI for purposes of receiving Medicaid.

V. Conclusion

In conclusion, all of these measures can make an important contribution for improving the economic well-being of older Americans. They are all "doable", even within the context of an austere budget. Cost considerations can be accommodated through phase-in periods or other means. Some measures may be advanced one step at a time because of their budgetary impact. But, this should not deter our nation from pursuing these worthy and necessary goals.

Finally, NCBA cannot stress strongly enough the importance of having a genuine income strategy that goes beyond COLAs for annual benefit increases. Without real improvement in SSI benefits, the overall economic situation for elderly Blacks will remain in critical condition. Therefore, NCBA reaffirms the crucial need for starting now to increase SSI above and beyond the annual COLA.

STATEMENT OF

SERGEANT MAJOR C. A. (MACK) MCKINNEY, USMC (RET.)
LEGISLATIVE COUNSEL

Mr. Chairman. The Non Commissioned Officers Association of the USA (NCOA) is a federally-chartered organization representing noncommissioned and petty officers of the Armed Forces of the United States. Its current membership is approximately 160,000 and representative of all military components, including active duty, reserve, national guard, retirees, and veterans. Many of the Association's most active chapters are located on or near military installations.

NCOA is concerned that a provision of the law, section 1382(f), Title 42, U.S. Code, considers an individual in receipt of SSI benefits for the disabled, ineligible for such benefits after being "outside the United States for any period of 30 consecutive days." Although the Association can subscribe to the wisdom of the legislation, it does not understand why Congress may not have considered the disabled child whose parent is in the military service of the United States.

These parents are directed under government orders to assignments outside the United States. If for periods in excess of nine (9) months, such orders are considered permanent changes in station (PCS) and may authorize servicemembers to have their families accompany them overseas for the term of the assignment. If a family has a disabled child eligible for SSI benefits in the United States, the eligibility terminates 30 days after departing the United States.

A case in point was publicized in the March 27, 1989, issue of NAVY TIMES. Reporter Grant Willis wrote of a soldier whose 3 year old child with cerebral palsy had her SSI payments terminated after the family was transferred overseas. In a letter to Representative Jim Slattery, Member of Congress from Kansas, the soldier warned that "if she does not receive any more SSI we are financially not able to meet all these goals (care, therapy and treatment) and she might regress."

The termination of SSI benefits, coupled with moving the family overseas works an excessive financial hardship on servicemembers and their families. Moving expenses, for example, take a terrible toll on the family budget. A recent survey completed by the United States Air Force attests to the high-cost related to a PCS. Only $1 for every $3 expended by the servicemember is reimbursable through the federal government.

In addition, whenever the U.S. dollar is devalued as it currently is, our servicemembers find it tough going financially to live on the civilian economy. Many are required to do so for on-post housing is usually not available for some months ahead. Although the military offers cost-of-living allowances (COLAs) to servicemembers' stationed abroad, the costs are still excessive.

Assignments overseas can be made even more fiscally difficult for enlisted servicemembers, primarily in pay grades E-6 and below, and their families, who were entitled to Earned Income Credit while stationed in the United States. This entitlement, as is SSI, is also terminated on their transfer to an overseas duty station.

The question may arise as to why a servicemember would want to jeopardize the continuation of such benefits by accepting an assignment overseas? And, too, why would he or she not leave the family in the United States?

The answer to the first question is simply one of necessity should the servicemember wish to further his or her career in the Armed Forces. Failure to comply with transfer orders, even under humanitarium or unusual circumstances, can lead to a discharge or separation from the military. And, for the second question, who really believes it's cheaper to maintain two residences even if one is located in a military barracks?

NCOA believes it to be only fair and equitable to amend the current law. The statute needs to reflect the unusual circumstance in which the servicemember parent of a disabled child in receipt of SSI benefits is required to comply with official orders of a family-accompanied assignment outside the United States. In this regard, NCOA advocates the early passage of H.R. 874.

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

STATEMENT OF

SENATOR DAVID PRYOR
Chairman
Senate Special Committee on Aging

Submitted to

SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS

With regard to

PROPOSALS TO IMPROVE THE
SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

May 30, 1989

Mr. Chairman, I appreciate this opportunity to express my concern over shortcomings in the Supplemental Security Income (SSI) program, particularly with respect to the lack of effective outreach to the many eligible elderly and disabled Americans not being served by the program. I applaud the distinguished chairman for focusing needed attention on problems with the SSI program.

Nearly two decades ago, the SSI program was established to help the nation's poor aged, blind and disabled meet their most basic needs. Authorized in 1972 and implemented two years later, SSI provides monthly payments -- a monthly maximum of $368 for an individual and $553 for a couple -- to those who apply and are within the program's nationwide eligibility requirements. Importantly, in most states SSI participation automatically confers Medicaid eligibility.

Currently, about 4.3 million Americans receive assistance under SSI, with approximately one-third or 1.4 million of them eligible on the basis of age. However, over the years studies have consistently found that about half of the nation's elderly and disabled poor do not participate. The major reasons are simply that they do not know that the program exists or how to apply for benefits.

Most recently, a January 1988 study conducted for the American Association of Retired Persons (AARP) found that only 51.1 percent of eligible elderly Americans were participating in the nation, with rates varying between 30 to 60 percent among the states. In my home state of Arkansas, for example, of the nearly 88,000 eligible individuals, only 40,100 -- less than 46 percent -- were participating.

A related AARP study, conducted by Lou Harris and Associates in 1986, found that over half of the potentially eligible poor surveyed had never heard of SSI or did not know how to apply for assistance. Less frequently cited reasons included an inability or unwillingness to deal with the long and complex application process, language barriers, the stigma of receiving welfare, the fear of loss of privacy and the perception of low benefits.

As the Chairman of the Senate Special Committee on Aging, I believe that the low rate of participation in the SSI program should and must be improved. Toward this end, on March 15th, I introduced S. 600 to require that SSA establish a permanent outreach program to inform elderly and disabled persons of their potential eligibility for participation in the SSI program, as well as to make a number of technical improvements in the program. These provisions are also included in H.R. 866, the proposed "SSI Benefits Improvements Amendments of 1989" and H.R. 867, the proposed "SSI Technical Amendments Act of 1989", legislation introduced by Representative Matsui, with the cosponsorship of Representatives Downey and Roybal, among others.

Last year, AARP and the Commonwealth Fund Commission on Elderly Living Alone joined forces with dozens of local agencies in three cities across the nation to get the word out to poor elderly individuals who were not participating in SSI. The project pioneered a number of innovative outreach strategies, making extensive use of the media, training, community education, and one-to-one counseling of potential applicants. In the three cities, SSA reported an increase of about 97 percent in applications and about 58 percent in awards. In the one city where the local SSA office fully cooperated, results were significantly better, with applications increasing by 157 percent and awards by 68 percent. Hearing of the dramatic success of the project, a number of other organizations in other cities, including the Central Arkansas Area Agency on Aging in North Little Rock, are planning to participate in similar outreach efforts next year.

In recent years, SSA itself has undertaken some outreach activities, but to a much more limited degree. In 1984, SSA did

a one-time mailing to potentially eligible elderly individuals. Since that time, SSA also has included an SSI alert to older and disabled individuals when they are notified of their eligibility for Medicare. However, many elderly slip into poverty as they become older, which may be long after they received the SSI alert.

To build on the success of public and private outreach efforts, without supplanting SSA's responsibility in this area, section one of S. 600 would establish a permanent SSI outreach program. Under this program, SSA would be required to notify Social Security recipients about SSI on an annual basis. As I mentioned, currently such notices are only sent at the time an individual becomes eligible for Medicare. Under this provision, notices would be sent when an individual applies or is awarded disability benefits, when they are notified about Medicare Part B eligibility, and annually thereafter. In addition, individuals would be notified of potential Medicaid and food stamps eligibility. This section also would require that SSA cooperate with other federal, state, and non-profit organizations who are engaged in outreach activities, such as those taking part in the AARP project. Finally, this bill would require SSA to evaluate the results of its outreach efforts.

This legislation would also make three technical improvements in the SSI program. Under section 2 of the bill, an SSI recipient would be permitted to exclude a modest amount of interest or dividend income from countable income. Under current law, an SSI recipient can have up to $2,000 in savings or an investment without losing eligibility. However, the interest or dividend on that investment is counted in determining eligibility. This section would disregard $120 in interest or dividend income annually, equivalent to a 6 percent rate of return. This disregard would increase by $12 each year through 1995 to keep pace with expected inflation.

Under current law, an SSI recipient can hold a life insurance policy as long as it does not have a cash value exceeding $1,500. The same limit is applied to a burial fund. Section three of the bill would raise the allowable amount for both the face value of a life insurance policy and a burial plot to $2,500 and extend current rules regarding recovery and waiver of overpayments when a recipient mistakenly uses a portion of the burial account for some other purpose.

At present, SSI eligibility for cash assistance under the program is determined, in part, on the basis of countable monthly income. Problems can arise when a recipient unexpectedly receives a pension check or some other form of earned income ahead of schedule, thereby raising the amount of

earned income that is counted that month. As a result, the recipient's SSI payment is reduced or even terminated -- not because his or her earned income actually increased, but because of the monthly eligibility determination method used by SSA. Section three of the bill avoids this problem by requiring that the monthly average of a recipient's annual income be used as the basis of eligibility determinations.

Like many others, I believe there are number of other changes that must be made to the program if it is to be truly effective. I am fully aware, for example, that the SSI benefit standard is woefully below the poverty rate and that the assets limits are far too low and have not kept pace with inflation. As a result, even those participating in the program are not always able to adequately clothe and feed themselves, nor afford decent housing.

Tragically, at this time our nation's massive federal budget deficit stands in the way of doing all that needs to be done to rectify these problems. However, we must continue to do all we can in this area. It is my hope that as we bring down the budget deficit in coming years we can make these needed reforms. I believe that S. 600 and today's hearing represent a vitally important step toward improving the effectiveness of the SSI program.

- MAY 30, 1989 -

TO: Robert J. Leonard - Chief Counsel -
House Ways and Means Committee
1102 Longworth Office Bldg.
Washington, D.C. 20515

SUBJECT: My Testimony for the House Committee on SSI -

FROM: Dorothy R. Stewart -
305 West 16th St., Apt.8
Vancouver, Washington 98660
(206) 693-2488 -

I am enclosing a summary of my background and a resume of my accomplishments. There is also attached an informational sheet covering the services I offer to my community as a volunteer. It seems that I have found my "niche" and am very grateful for all the benefits I have coming my way. Though the "battle" never will end, I am now enjoying it more.

Thank you for this opportunity to testify.

In 1981 some brutal truths began to surface in my life. I was unable to go out and earn my keep. I had no money, no savings, no assets. I did have 3 choices, or so it seemed to me - and one final option -

I could either go into a convent -

I could become a "bag lady" -

I could take a flying leap off the Interstate bridge INTO the Columbia River —

None of these choices were viable for me - the option I chose was to forget my pride and apply for welfare assistance -

What follows is my story -

- May 30, 1989 - Testimony of Dorothy R. Stewart -
continued.....

I have been a recipient of SSI - Supplemental Security Income - for almost 6 years. The name given to it, supplemental security income is somewhat of a misnomer in my case - it is NOT supplemental to anything - IT IS IT - the security part is correct as is the income part - it is, indeed, my security income !!

I am a 58 year old single woman. I was not eligible for any Social Security benefits when I first applied for assistance through our state department of social and health services office (DSHS). I was told I must apply for SSI at the same time I was applying for state aid - in Washington state this is called General Assistance-Unemployable (GAU). I followed each step as ordered for me - I do not know if this is still true for all people applying for state aid.

I applied for
The state assistance and the SSI benefits in August of 1981. I had been 5 long months without any income, aside from food stamps, A terrible, frightening time. The GAU benefits began almost at once. The SSI was turned down - I appealed it - it was denied once again - it was now mid-1982. I continued on GAU all during this time - the amount was well under $300.00 - I did receive food stamps on which I managed to survive along with the help of several wonderful friends who came through regularly with what I called "care" packages. My wonderful landlord and his family carried me without any rent for 5 months - I finally received a court date for the federal Administrative Law Judge hearing to take place in April of 1983. This was the third level of appeal and just about all I could do on my own. The ALJ heard my case and ruled in my favor in May of 1983 - my first SSI check came on the 1st of July - 1983. PRAISE GOD !!

During this 21 month waiting period, before my SSI kicked in, I had finally had my Section 8, subsidized low income housing come on line. My rental payments now were only 30% of whatever my current total income was - a great relief and this freed up over $100.00 a month. By July of 1983 when my SSI check arrived it was considerably more than that GAU check had been. I also had all medical needs met with the assistance of the

(more)

the state issued Medicaid coupons. This program is called the Categorically Needy Program or CNP in our state. This benefit all by itself is a great boon to those of us with chronic ailments and disabilities. A real great boon !! All I had to be concerned with was if my physician or physicians or therapists would accept the coupons - most of them do . In January of 1988 our state legislature voted in the new dental care options. It was great !! I had not been able to access a dentist for 6 years and I desperately needed care. However, this dental care has had mixed benefits. It is limited to only a very few local dentists who agree to accept the medicaid coupons. As I understand it, all dentists are required to accept these coupons. When I recently checked out the nearby dentists here in Vancouver I discovered, to my dismay, that either their "quota" was full or they just plain did not accept new patients who had only the medicaid coupons. The reasons being, or so I was informed, that DSHS only paid about half of the going rate for any one procedure and even then were very slow in paying. <u>This must be changed</u>. I see this as discrimination -

The other big problem I see with SSI/medicaid benefits is one of lack of ready access to our mental health system. There is only 1 local provider of services to the mentally ill in Clark County - Elahan center for the mentally ill. If you have a crisis or if you feel the need for access to a medical doctor who is also a psychiatrist, you must wait a long time to see one of the team of psychiatrists who take turns at Elahan. I was very fortunate back in 1984 when it became imperative that I see a psychiatrist and I discovered that a new doctor in town was just opening his practice here and would accept me as a "test case" - it has proved most beneficial to and for me and I am forever grateful to this fine man for his help. I have a condition diagnosed in the DSM III as "generalized anxiety disorder." I have a chronic pain syndrome also - He has helped me to get off several different narcotic pain pills and Valium. I am so grateful. Elahan has a long waiting list and as a rule see only the most serious and severe crisis people. It is done by priority -

There is a Psychiatric Nurse Practitioner on duty or available 24 hours a day, 7 days a week at our downtown hospital, Vancouver Memorial. Access to this service is not well publicized. If it ever became well known, she or he would be swamped - as it is - she or he is very busy. This person needs help and assistance or back-up from the emergency room team much more than she is now getting.

I came into this community of need early in the 1980's and after Mr. Reagan's "safety net" was allegedly in place. I found many holes to fall through along the way and would have fallen all the way out of sight except that I learned who, how, when and so on in order to survive. Learning the correct protocol of the different agencies involved in delivering services to those of us on SSI, making sure that the "paper" got shuffled in the correct way, and just plain learning to talk to the person who had the most clout saved me from slipping out of sight never to be seen again. I also learned and kept abreast of the current state and federal legislation all during this time. I have had the benefit of a n excellent education along the way in the years preceding my going on public assistance. I graduated in 1979 with a bachelor's degree from The Evergreen State College-Vancouver program. This school has what is known as an alternative way of learning. Indeed it has. I learned to research, study, to learn and to never stop learning. To take every experience, good or bad, and to learn from it !!This I have done. I had become involved in the Disability Rights movement of the late 1979's. This was all prior to my becoming a part of the disabled community myself. Not everyone has the opportunity of a good education like I did. Not everyone has the opportunity nor is able to learn the techniques from experts like I did. The government folks, the workers, have such a crowded case load that they just cannot take the time to be human or as compassionate to every single person filtering through their offices in a days time. There is also the question of "burn-out" at all the levels of officialdom. Indeed - the caregivers - the real people

on the firing line are usually never in the seat of power. The ones in power are usually content to just shuffle paper, do their job, and go home at night with a clear conscience. Of course, this is one of the requirements, isn't it ? Somehow, some way, somewhere this all must be changed.

I have been an advocate for the low income older women for several years. I find the same problems cropping up with just about every person I meet up with.

In late 1983 and early 1984 as it became evident that I would be dealing on a more or less regular basis with the bureaucracy I determined to keep abreast of all the legal requirements or changes transpiring on a local as well as a federal level. I determined that it was not necessary or even feasible to have a panic attack every single time I had to access the governmental offices for whatever reason and to learn to understand the processes of government better. To learn to know the individual workers as well as I could, and to become their advocate too. After all, aren't most things a two way street ? There was no way I could or would continue to live in a state of tension and/or anxiety over this - no way - there must be an easier way.....I set out to find it - I am still searching .....

<u>What I have discovered</u> -

1.) There is no easy way.....
2.) Anyone needing/wanting assistance of any sort must be willing to fill out reams of paper just in order to qualify, and even then, it seems to take forever.....
3.) I have learned to keep a daily log of events, the people talked to, the time, place and so on - what was discussed and any conclusions reached, etc. I have found this keeps the provider accountable - it keeps things a bit more personal for both me and the service provider. Along this same line, I have made sure to find out just who I am talking with, their position and so on.
4.) I have learned to manage on $375.55 a month cash income along with $26.00 a month in food stamps. I pay $75.00 a month for my nice, airy 1 bedroom apartment which could rent for upwards of $255.00 a month, this includes our PUD or power, the water and city sewer and weekly trash pickup. I pay the gas company $21.00 a month for my heat. My phone runs me at least $50.00 amonth no matter what.

I pay $8.50 a month for my daily newspaper. I have no cash assets, no bank account.

What all the above has boiled down to in my case is one of my learning my priorities - what is the most important thing ? Then it has been realizing just where my security lies - that of feeling secure in my own self. I might add that as the years go by - o ne realizes - at least this one human being realizes that my pride is worth ZILCH - it could not pay the rent - it did not put food on the table - it did not pay my other bills - so the lessons have been learned the hard way - always the hard way - but - as a result - they have been learned well !!

The state of Washington provides an 800# to our state capitol in Olympia. This is what is called the prior authorization number. This service has been somewhat awkward to access at times. I have recently discovered that there are only 2 operators on line at any one time. And one supervisor. This is for the whole state. Not a good way to run things at all. These individual operators must pull each person's file each time a service is requested. For example: when I need transportation to and from a medical providor here in Vancouver, I call the 800# and tell them the details, they check my file, clear it okay if necessary with the supervisor, and after I hang up, call our local cab company to approve the transportation. The medical, dental and/or other therapy treatments are approved by this same number, but by having the service provider call Olympia for prior authorization. All of this was working quite smoothly up until about a month ago - when for a very weak reason they denied me my transportation to and from a service providor, and all without any prior notice, to me. I am in the rpocess of appealing this at the present time. It is most arbitrary and based on hearsay. So it goes - Olympia - the state DSHS needs an overhauling from the top down. It has gotten too big - too many frogs in a very small pond. More accountability is needed on all levels. Especially from them to us out here on the receiving end - so that we ~~are~~ not made to feel like we are asking any sort of a personal favor - it is all very demeaning and so terribly tiresome.

Again, my thanks for this opportunity to testify - I await the outcome of the committee hearings with eagerness.

Dorothy R. Stewart

DOROTHY R. STEWART
RAINBOW RESOURCES
305 WEST 16TH ST., APT. B
VANCOUVER, WASH. 98660
(206) 693-7488

A BRIEF SUMMARY OF MY BACKGROUND -

DOROTHY R. STEWART - born in Rochester, New York, October 16th, 1930 - moved to West Los Angeles, California with my folks in early 1947. Graduated from University High School in June of 1948. I attended and graduated with an Associates in Arts degree in Pre-Nursing, from the Santa Monica Junior College in June, 1950. I entered the California Lutheran Hospital School of Nursing, in downtown Los Angeles, in September of 1950 - I also registered at the University of Southern California at the same time. I was on what was called a 5 year degree program and would have had my degree in nursing and a Bachelor of Science degree had I been able to finish. I dropped out in the fall of 1952 due to serious illness. I married in 1954, my only son was born in 1956. We moved to Vancouver, Washington in 1966. Divorced in 1974. Returned to the University (Portland State) in fall of 1975, dropped out in early 1977 just short of graduation, again due to very serious illness and an ever worsening disability. Returned to college life once more in fall of 1978 at the Evergreen State College-Vancouver Program. I received that long sought Bachelor's degree in June of 1979 (a great day!). I went to work for Clark County on a special CETA 12 month project as the 504 Planning Intern (Civil Rights for the Handicapped). The job was completed in September of 1980. On unemployment, no work available and could not work anyways due to increasing difficulties with my health. I applied for SSI (Supplemental Security Income) in 1981, and other entitlement programs. I am at present living on this very small fixed income, receive food stamps and Medicaid (not Medicare) coupons, and am on Low Income Housing. Due to these rather marvellous benefits I am able to live quite comfortably and secure and am able to perform some most helpful (to me) public service as a community volunteer and activist.

References upon request -

I HAVE BEEN ASKED: WHAT IS- RAINBOW RESOURCES ?

I make CONTACT - I LISTEN - offer COUNSEL or ADVICE (which you can accept or reject) - I try to COMMUNICATE COMPASSION - offer COORDINATION and COOPERATION through the use of my NETWORKING TOOLS - I do any additional RESEARCH into the need or needs expressed to me, again by using my network of RESOURCES - I am then able to make the REFERRALS that are necessary -

There is absolutely NO FEE for any of the services I offer -

I feel I offer a form of, a rather unique type of CLEARINGHOUSE - where I can represent and advocate for, primarily, the low-income older women.

I TRY TO BE:

- as non-judgmental as is possible, whatever the circumstances -
- and to show as much "unconditional love" as is possible, considering my own humanness -
- the channel of Christ's love to these women, AND..... to
- have, as obvious as is possible, to this "helpee" that, above all, I CARE !!!! "THAT THERE IS ALWAYS A WAY...."

Thank you -

Dorothy R. Stewart

DOROTHY R. STEWART -

"I gain strength, courage and confidence by
every experience in which I must stop and
look fear in the face...
I say to myself, I've lived through this and
can take the next thing that comes along...
We must do the things we think we cannot do."

- - Eleanor Roosevelt

DOROTHY R. STEWART
RAINBOW RESOURCES
305 WEST 16TH ST., APT. B
VANCOUVER, WASH. 98660
(206) 693-2488

TESTIMONY REGARDING SSI PROGRAM

Submitted By: Advisory Board
Department of Human Services
County of Summit
Akron, Ohio 44308
May 24, 1989

In April of 1987, our Advisory Board was empowered by county officials to perform a General Assistance (Relief), Health and Decency Standard Study. The primary focus of the study was to arrive at a recommendation for the county officials regarding the monthly payment level for General Assistance recipients. However, several additional recommendations were also presented; one of which we would like to share with you.

In July, 1987, the County of Summit had 8700 recipients on the General Assistance payroll. Two hundred thirty-seven (237) were approached personally by Advisory Board members and asked to complete a forty-two (42) item questionnaire. Two hundred twenty-three (223) questionnaires were successfully completed and compiled.

A popular perception of the General Assistance recipient is the picture of the young, able-bodied individual who is shirking work responsibilities. Of course, we are learning more and more that this person is hampered by lack of an employment opportunity in which they can perform. This was confirmed by 119 of our respondents citing lack of education or training as one of the main reasons why welfare recipients are unable to get off welfare. Eighty-one (81) reported less than a high school education.

However, another variable we examined involved age and physical/mental health problems. Twenty-seven of our respondents were 50 years of age or older; five were sixty plus. One of those reported he was hoping to retire soon and collect Social Security.

When asked what were their problems in finding employment, nineteen (19) stated age and thirty-nine (39) stated physical/mental problems. In response to the direct question: "Do you have any medical problems that are keeping you from a job:", sixty-seven (67), or 30%, stated yes. Back, spinal and orthopedic problems led the list of specific concerns.

At the same time that our Advisory Board was completing our study, the Ohio Department of Human Services was implementing policy allowing local departments the option of creating "SSI Flip-Over" programs. The purpose of the program, officially labeled SSI Case Management, is to assist identified General Assistance and other low income individuals with the process of applying for and being awarded SSI payments. Our study results lead us to recommend to county officials that the local department pursue the establishment of this program.

Summit County began our SSI Case Management program in November of 1987. Three staff members experienced in both the Income Maintenance and Social Services programs were selected to work with the clients by preparing appropriate and required case histories and assisting with filing for SSI and reconsiderations as needed. As of April, 1989, 1,274 active public assistance clients have been referred to the special unit; 709 have been evaluated for SSI with 426 applications being filed with the Social Security Administration. Approvals by Social Security included 395 for SSI and 31 for the Title II disability program. The county has also established relationships with the local state office of the Bureau of Vocational Rehabilitation which has resulted in 61 individuals filing for assistance from this agency. This is unique to Summit County.

The unit has also evaluated the denials of 425 clients for SSI benefits. Of these cases, 227 were submitted for administrative reconsideration and 33 have been sent to the administrative law judge.

An additional side benefit to the county has been the transfer of 356 cases from the General Assistance Medical Program to Medicaid. In Ohio, the local level must pay a portion of General Assistance program costs. So, a transfer to the federal/state Medicaid program is a direct benefit to the county since the average monthly medical costs for these individuals was totalling $400 in October, 1988.

The county has also gained a greater reimbursement for the interim General Assistance provided while the SSI Application is pending. To date, the repayment figures total $274,770 for the eighteen months of program operation. This represents an increase of 30% over previous annual repayment amounts. Our goal is to provide speedier consideration/ approval by the Social Security Administration so that the necessity for interim assistance is negated. This then would result in additional administrative savings.

In order to further enhance our efforts to establish proper and timely assistance for individuals in need, we are now working with the community hospitals and have stationed intake workers in their patient account departments to begin the application process on-site. This should facilitate the shortening of the application process and proper utilization of local, state and federal funds.

In summary, our Advisory Board strongly encourages outreach efforts to reach potential SSI recipients. We feel that programs similar to ours have an appropriate place within the public assistance structure, particularly since the eligible population may already be known to us as recipients of partial aid; such as food stamps only or health care supplements. We applaud the efforts of the Ways and Means Committee in examining the issue and thank you for your attention to our testimony.

Respectfully submitted,

Virgil Collins

Virgil Collins
Chairperson

THE
Villers
ADVOCACY ASSOCIATES

1334 G STREET N.W./WASHINGTON D.C. 20005/(202) 737-6340

June 5, 1989

Thomas J. Downey
Subcommittee on Human Resources
House Ways and Means Committee
B317 Rayburn House Office Building
Washington, DC 20515

Dear Mr. Chairman,

The attached letters are submitted for inclusion into the record for the hearing your Subcommittee held on May 30, 1989 on Supplemental Security Income issues.

These letters, which we received from all over the country, tell first hand stories of the difficulties of living on SSI and dealing with the SSI program. I hope the stories related in these letters are helpful to you and the Subcommittee Members as you look for ways to improve the program's ability to help those in need.

If we can be of any assistance to you in this area, please do not hesitate to contact me or my staff at 737-6340.

Sincerely,

Ronald F. Pollack
Executive Director

4 Chestnut Street
Randolph, Vt. 05060

A.S.A.P.
1334 G St. N.W.
Washington, D.C. 20005

Dear Sirs:

This is an answer to your question concerning seniors who are "struggling to get by" on SSI. I want to share my experiences.

I am 75 years old and first received Social Security disability benefits., in 1970, because of health problems. A few years later I was able to receive SSI. At age 65 the payments became regular Social Security benefits.

As of now I receive $375.00 a month from Social Security, plus $73.00 from SSI. With this I pay for utilities, the water bill, and life insurance. My sister (Mary) and I live together and share the grocery buying. There are, of course, personal expenses. Also each month I put a certain amount aside toward property taxes and house insurance. As you can imagine, there is little left at the end of a month, no matter how careful I am.

I do receive Fuel Assistance, but my sister has to pay most of the fuel bills, although I try to put something towards that when I can.

A few months ago I applied for Food Stamps, and my application was approved. Then I was informed that I was not eligible. "They" had compared my income with my sister's (see her letter previously sent), and had decided that -- between us -- we had "too much money." Therefore I was <u>not</u> entitled to Food Stamps.

Bureaucratic reasoning baffles me. I was informed, on the phone, that a man and woman living together, although not married, could receive Food Stamps. Or two men or two women living together could be eligible. But -- two related people, living together, are <u>not</u> eligible. Why?

I was also informed that if my sister and I bought our groceries separately, prepared meals separately and didn't eat together (even if in the same house), I could receive Food Stamps. (A signed statement to that effect would be needed.) That was so utterly ridiculous I didn't even consider it. The system is not fair.

My Social Security seems a menial amount; the SSI a pittance. In these days, it is almost impossible to make ends meet. Each month more ground is lost. (For me, there are no other financial resources, such as savings account etc.)

I am not sure this will help in your survey or not. I am relating my experiences for what they are worth.

Sincerely,

Elizabeth W. Clapp

Elizabeth W. Clapp

SAWYER COUNTY AGING UNIT
Located at Fifth and California
P.O. Box 502, Hayward, Wisconsin 54843 • 715-634-3000

17 May 1989

A.S.A.P.
1334 G Street, N.W.
Washington, D.C. 20005

SSI

In the State of Wisconsin, individuals living on SSI are at $471 per month. If they are married, the couple must live on $718 per month. They are also given a Medical Assistance card.

If two people on SSI get married, often, they are no longer eligible for SSI or Medical Assistance. They are still within the resource levels, but the income level exceeds the $718 per month. They are also no longer entitled to the Medical Assistance benefits.

We have a couple that were in their late 70's. She has an income of approximately $325 a month and he has about $450. When they were married, their combined income is $775. They no longer qualify for SSI or Medical Assistance. In order to qualify for medically needy, they must spend $1104 each six month period, then Medical Assistance will pay the balance of the medical bills for that six month period.

In northern Wisconsin, where winter starts about October and ends in May, trying to live on $471 is very difficult. The heating costs alone take a big percent of this income.

It is not uncommon to travel 100 or more miles for medical treatment. Those who are over the SSI level cannot afford to go for medical treatment. Most of them do not have adequate transportation and cannot afford to keep a decent vehicle.

Under the spousal impoverishment guidelines, the spouse at home will be able to keep at least $780 a month to live on, while the couple on SSI are expected to live on $718 per month.

SSI and Medical Assistance are wonderful programs. The people who receive them are really in need. They have no savings accounts to fall back on. The people in this area worked long hard hours at low wages with no benefits, no pension plans, etc. They may have saved a little toward their "old age." Many of these people are living on $200 a month, but have over the $2000 in the bank. They are afraid to spend any of that because they may need it. They see SSI as a welfare program and they are too proud to accept welfare.

There are many people just over the income limit who are really struggling. They cannot afford medical care. They don't have the $75 deductible for the Part B Medicare, they cannot afford a prescription, and the $560 Part A deductible would wipe them out completely. If you are living on $525 a month, you cannot afford those kinds of deductions. If you haven't been sick before, you don't know about the 14 page application for Medically Needy.

When we let our vulnerable population struggle without adequate help, they become more frail and end up in nursing homes. Then our costs are a lot greater and we may have been able to prevent it by giving them a better quality of life with a few additional resources while they were still in the community.

Arlene Lessard

ARLENE LESSARD COORDINATOR

al

5-18-1989.

A.S.H.P.
1334. G. Street N.W.
Washington, D.C. 20005

Dear Sirs,

Yes. I have been denied S.S.I. out of North Platte because My Social Security Check & My Wife's were too high.

Today I talked to the Social Security office. they said I would have to get along on what we were getting.

I get $388.00 & My Wife get $368.00 Our Medication is over 125.00 a mo. My Wife has Alzheimers Disease and we have had to spend all of our savings of $125.000.00 besides what it takes of our Social Security Checks. with what rent we pay then all the utilities and pay for medication for the both of us and still have enough for Clothes & food. we have to go without many a time. we have to decide if we eat or get Medication. The Wife has had Alzheimers for 6 years and I take care of her with no help. There isn't enough money to hire some one to stay with her even a few days to let me get away for a little while.

If any thing can be done I would sure Appreciate it. I try to Mow lawns ect do work for the Neighbors but that is very little. I am 74 and have had 3 heart Attacks & also have a Pace Maker.

Thank you

Harris L Reed Sr.
P.O. Box 294.
Grant, Ne. 69140

May 21, 1989

Congressman Tom Downey
Human Resources Sub-Committee
Washington, D.C. 20005

Congressman Downey:

Concerning your hearing on SSI May 30, 1989.

I am a Senior citizen with a total Monthly income of $359.00 My only assets consist of one automobile 1969 Model and furniture for a one bedroom Apartment.

I was denied SSI and Medicaid because my income seems to be Ninety cents (90¢) to High.

To demonstrate the problem of living on this income I need dental work done, also, an operation on both knees. Because there is not enough money after rent and groceries, I can have neither.

I hope some positive solutions will come from these hearings and reform of the inequities will be made.

Sincerely,
Bertha E. Richardson

ADDISON COUNTY COMMUNITY ACTION GROUP
POST OFFICE BOX 186
MIDDLEBURY, VERMONT 05753
(802) 388-2266
(802) 388-4802
(802) 877-2521

A.S.A.P.
1334 G Street, N.W.
Washington, D.C. 20005

May 24, 1989

Dear A.S.A.P.:

This is in response to your request for testimony on the inadequacies of SSI.

Fred and Frances Hutchins own a small dairy farm in Shoreham, Vt. (Mailing address is Bridport, Vt. 05734) She is 62, and he turned 65 in April. Mr.Hutchins milks 21 out of 32 cows. They have the usual run of farm equipment which is in perpetual need of repairs.

Mr.Hutchins also draws sawdust in a 1971 two-ton Chevy truck. He usually clears $200/mo. from the sawdust business, but recently he needed to put this right back into the truck. Often, this money has to go into the farm - for grain, etc.

Enclosed is a copy of the April '89 milk check which shows net earnings of $0. Four months out of the year, the check can go as high as $1000., but usually it's a lot less.

Mr.Hutchins says, "If it wasn't for food stamps, we'd starve to death."

Mrs.Hutchins suffers from severe emphysema. Early in 1988 she applied for Medicaid and SSI. She was found medically and financially eligible for Medicaid. She was denied SSI because the cows and farm equipment were considered as resources and put her over the limit.

Vermont Legal Aid appealed this decision, but it was upheld. They are continuing the appeal.

Mr.Hutchins applied for Social Security benefits last year. He was told that he wasn't eligible beacuse he didn't have enough quarters. He just applied for SSI because he is 65. The SSA told him he will probably be denied for the same reason his wife was - excess resources. He is applying anyway in hopes that if an appeal is successful, he will be able to get retroactive benefits.

It is unquestionable that Mr.and Mrs.Hutchins are living below the poverty line and desperately need the help that SSI could give. SSI resource regulations are clearly unjust and need to be changed.

Between the lines of this letter is the tragedy of the small farmer in Vermont and why they sell out and what kind of lives they lead when they don't.

Sincerely,

Rosalyn Chirnoff

Agri-Mark

Agri-Mark, Inc.
P.O. Box 5800
Lawrence, MA 01840

RETAIN THIS CHECK STUB FOR YOUR TAX RECORDS

DATE 5/19/89

No. 540628

FRED OR FRANCES HUTCHINS

MEMBERSHIP NUMBER	001074	PLANT NUMBER	930	ZONE	19	CHECK TYPE	FINAL CHECK

POUNDS BY PERIOD	TANK 17	TANK	TANK	TANK	TOTAL POUNDS	MA 3.5 BLEND PRICE	BASE EXCESS PLAN BASE → EXCESS →	POUNDS	3.5 PRICE	APR. MILK EARNINGS
1-15	6494				6494	↓				
16-31	5003				5003					
TOTAL	11497				11497	12.069		BLEND AMOUNT →		1,386.54

BF TEST	3.40				
BF ADJ AMT	17.36-				

BF DIFF	1.510	
TOTAL BF AMOUNT →		17.36-

GROSS EARNINGS & AMI PREMIUMS/CREDITS $1,403.67 POUNDS 11,497
YOUR PAY PRICE PER CWT.- $12.21, EXCLUDING RCMA

GROSS EARNINGS
1,369.18

DEDUCTIONS AND ADJUSTMENTS	AMOUNT	DEDUCTIONS AND ADJUSTMENTS	AMOUNT
AGRI-MARK PREM/CREDITS			
AGRI-MARK .300/CWT	34.49		
SUBTOTAL	34.49		
ADVANCE	287.45-		
SUPPLIES	400.00-		
DUES VOLUME.06/CWT	6.90-		
DUES MONTHLY	30.00-		
PROMOTION .15/CWT	17.25-		
HAUL 0.220/CWT	25.30-		
STOP CHARGE	67.50-		
FARMERS HOME ADMIN	569.27-		

NET ADJ.
1,369.18-

NET EARNINGS
$******.00

YTD MILK DOLLARS
4,503.44

YTD GROSS PRODUCTION
34,894

240

May 24 - 89

To: Whom it May Concern.
Please allow me to remind
you to see what can be done
to improve the SSI in Georgia.
I'm involved in the program
I only get $81.00 per month and
the Limit is ~~on~~ only $388.00 how
Can a Widow Woman live and
Pay rent & other bills at age 77 yrs
old on this kind of money. Please
see what you can do.
Thanks,
Floy Shelnutt

2240 Peachtree Rd #617
Atlanta, Ga 30309

A. S. A. P.
1334 G Street N.W.
Washington, D.C. 20005
Gentlemen—
It has come to my attention that your room will be going to a hearing on the inadequacies of S. S. I. A am a tenant in a high rise for "seniors" Many of my neibors cannot pay their bills from month to month, and are constantly in debt. These people are not drifters or homeless, but have worked all their lives, and have made many contributions to society. I feel that anything you can do to raise their standard of living will contribute to making their lives more fruitful.
Many thanks for your dedication to this cause

Most sincerely
Anne Pitone

May 25, 1969

Clara Galdgeon
3128 D Briarcliff Rd
Atlanta Ga. 30329

A & A P
1334 G Street NW
Washington DC
20005

Gentlemen:-

I am a senior citizen and have many friends in my age group who are living on very fixed incomes.

Many of these folks have great difficulty in the past and need help in a decent living now.

Please review the S.S. benefits so that these people have a better way of life.

Yours truly,
Clara Galdgeon

5465 Suwanee Dam Rd
Suwanee, Ga 30136
Norman Horowitz

May 26, 1989.

A.A.A.R.P.
1334 G. Street NW
Washington DC 20005

Gentlemen:

Re S.S.I.

Of my own knowledge, I know of people presently existing on S.S.I. It is a shame that our government still expects the over 65 to exist on this level of income. If by chance the recipient is handicapped the problem is far greater.

It is simply an impossible existance if such people must rely on this limited budget. I appeal to the committee's sense of fairness to increase their income beyond a subsistance only level.

Respectfully
Norman H Horowitz

2170 Cheshire Bridge Rd N.E.
Atlanta, Ga 30324
May 26, 1969

A S A P,
1334 G St N.W.
Washington, D.C. 20005

Gentlemen,

I happen to be a tenant in a high rise in Atlanta and know some people who are struggling to get by on their S S I

As a senior citizen I can sympathize with those people and feel that the monthly level should be increased so that they can live a decent life.

I hope that you will see to it so this matter can be reviewed

I would appriciate your kind attention to this vital matter.

Sincerely,
Dorothy Figen

May 24, 1989

A.S.A.P.
1334 G Street, N.W.
Washington, D.C. 20005

Gentlemen:

We submit the following for inclusion in testimony in conjunction with SSI hearings in Congress:

SSI Problem Issues

1.) Disability Qualifications
2.) Definition of Income
3.) Treatment of Homebound
4.) Recognition of Client Rights

Case 1

Timothy Daniel Lewis:

Tim is about 35 years old and cannot get financially adequate employment due to a learning disability. In addition he has been suffering from the physical problems of a lack of hearing in one ear and a gum infection which has resulted in the loss of all his teeth. He has managed to obtain part-time employment at the Dona Ana Community Center doing janitorial work. He applied for SSI support and employment assistance from the Dept. of Vocational Rehabilitation. However, although Tim suffers the consequences of his learning disability, he was sent to a doctor selected by the Social Security office and this doctor claimed that Tim's problem is not a disability. Therefore, he is caught in a catch-22 of financial deprivation.

Case 2

Jacobo and Elizaida Barela:

Jacobo and Elizaida suffer from various physical problems and their medical and prescription expenses have seriously drained their social security income. They have no bank account or other resources that would count against them. However, when they went in to pick up an application from SSI, they were told "don't even think about applying" which is a violation of client rights. They were informed that the money deducted from their check which goes to their medicare coverage is counted against them as income. They have no control over this deduction and never see the money. Yet it is those few dollars which have shut them out of assistance.

Case 3

Gabriela Escalante:

> Gabriela is an elderly widow, homebound due to arthritis. Her brother attempted to pick up an application form for SSI and was told that Gabriela had to come in and get the form. He explained his problem to a volunteer worker at the Dona Ana Community Center who then called the social security office. The SSI worker stated that the only alternative would be a telephone interview with Gabriela. The volunteer informed the worker that Gabriela couldn't concentrate long enough for a lengthy interview. The worker then stated that an interview could be conducted over the phone with one of Gabriela's relatives. Why can't a relative pick up the application form and return it later? Also why can't the social security office send out representatives to homebound applicants to conduct interviews?

The above cases are just a very small sample of the problems faced by the elderly and disabled in Dona Ana County, New Mexico. Most are very frustrated with a system that does not allow them to become at least somewhat independent. Actually, they feel that the system does not exist for them.

Many elderly and disabled are Hispanic and a lack of caring for the minority, particularly Hispanic, elderly is and has always been a national disgrace.

The system has to work for all people. It must become available and understanding of the frustrations of disabled and elderly people who have as much right to live in dignity in Dona Ana New Mexico as those same applicants have in New York, Chicago or even Albuquerque, New Mexico.

New Mexico is a poor state, but it is rich in history and culture. Many of those denied services are responsible for the history and culture of southern New Mexico. We are proud of the people of this part of the state. They are hard workers, who will refuse to take from the government until desparation overcomes them.

I am Lynne Mockler who has been working as an advocate for the elderly for over ten years. I will tell you that the elderly of the southern part of New Mexico are people who I found warm, gracious, gentle but determined. I am proud of the people of southern New Mexico and angry that they are treated so poorly in the last years of their lives. Most are extremely dependent upon their families who give care and assistance better and more than any other people I have known. Yet, there comes a time when financially, it hurts and in this poor state, it hurts even more.

Southern New Mexico, particularly Dona Ana County, must become more vocal in response to the needs of the poor and elderly.

There is a growing sense of despair and anger, but pride is one of the major factors in our inability to organize advocacy groups.

Most people will try to get into the system and then when denied for whatever reason, politely say okay and give up.

This is wrong and nothing more can be said about it.

The elderly and disabled of southern New Mexico need your help in overcoming the shortfalls.

We respect your consideration of the above and thank you for your attention.

Sincerely,

Lynne Mockler, P.O. Box 1581, Las Cruces, NM 88004
Linda Hobbs, P.O. Box 22, Dona Ana, New Mexico 88032
State Senator Mary Jane Garcia (D), Dona Ana - P.O. Box 22, Dona Ana, NM 88032

1

WIN SENIOR ACTION COALITION
OF GREATER CINCINNATI
740 CIRCLE AVENUE
CINCINNATI, OHIO 45232
(513) 541-4109

Susan Kinoy
Villars Foundation
1334 G St. N.W.
Washington, D.C. 20005

May 26, 1989

Dear Susan,

Enclosed are some stories you may be able to use for your SSI testimony. All of the people have given their permission to use their names.

Sincerely,

Julie Kline

Julie Kline
WINSAC Staff

SSI Testimony

Ms. Anita May lives in Cincinnati, Ohio. She began receiving Social Security in 1975 after she turned 62 years old. At that time she lived on about $250. a month. She did not know about SSI until 1984, when she received a notice in the mail from Social Security telling her she could apply for SSI.

Initially an attorney assisted her in getting her SSI. In March of 1988, her SSI was cut off because she had not reported to the SSI office. She has no recollection of ever having been asked to do so. Her son took her to the SSI office after her SSI check was stopped. She was reevaluated and told that her check would be mailed in two weeks. She never received a check or any correspondence since that time.

Ms. May now lives alone on $278. a month from Social Security. She does not receive Food Stamps or Medicaid. She is 75 years old and too ill to deal with fighting for her SSI.

Ms. Willa Spikes, age 61, lives alone in Cincinnati, Ohio. She has a permanent, job related injury verified by doctor's reports. In October, 1988, her workman's compensation ended. She first applied for SSI in January 1989 and was denied based on a doctor's report. The doctor agrees that the report does not reflect what he said. SSI maintains that she only has arthritis. When she was working, she fractured her back, shoulder, and two fingers. She has constant pain in her back and legs, wears a brace, and sometimes stays in bed for two or three days at a time. She does have arthritis, as well as depression and a nervous condition.

She has no income at this time. She receives Food Stamps and has used up all her savings. She reapplied for SSI in May 1989. She was not given any information about SSI emergency funds, but was advised to go to the welfare department instead.

SSI Testimony

Ms. Beulah Doggett, age 76, also from Cincinnati, Ohio just learned how she could apply for SSI last year from her social worker and friends. She had never been given any information by Social Security about SSI even though she has received a social security check for many years.

Even with SSI, $16. worth of Food Stamps, medicaid, and subsidized housing, her income is inadequate for all but the most basic living expenses.

Income:		Expenses:	
$384.	Soc. Sec.	$ 97.	Rent (actual)
4.	SSI	120.	Food (estim.)
16.	F.S.	20.	Laundry (estim.)
$404.	Total	30.	Telephone (estim.)
		25.	Clothing (estim.)
		25.	Household items (est.)
		50.	Transportation (est.)
		10.	Items not covered by Medicare or Medicaid (est
		20.	Personal Items (est.)
		$397.	Total

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